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ABSTRACT

This document collects the 12 monthly issues of Volume 30 of "Exceptional Parent," a magazine focused on practical advice for parents of children with disabilities. Most issues include a focus topic as well as articles on other issues, columns, reviews, and letters. The issues focus on the following areas: (1) an extensive resource guide; (2) early childhood; (3) promising medical research; (4) mobility; (5) recreation, sports, and play; (6) technology in education and daily living; (7) adolescence as a time of change, challenge, and transition; (8) health care; (9) education; (10) toys; (11) technology; and (12) family, friends, and the community. (DB)

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Exceptional Parent, 2000.

Rick Rader, Editor

Volume 30
Numbers 1-12

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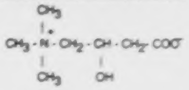
Description
CARNITOR® (Levocarnitine) is (R)-3-carboxy-2-hydroxy-N,N,N-trimethyl-1-propanaminium hydroxide, inner salt. Levocarnitine is a carrier molecule in the transport of long-chain fatty acids across the inner mitochondrial membrane. As a bulk drug substance it is a white powder with a melting point of 196-197°C and is readily soluble in water, hot alcohol, and insoluble in acetone. The pH of a solution (1 in 20) is between 6-8 and its pKa value is 3.8. Its chemical structure is:



$$CH_3-\overset{\overset{CH_3}{|}}{\underset{\underset{CH_3}{|}}{N^{+}}}-CH_2-\underset{\underset{OH}{|}}{CH}-CH_2-COO^{-}$$

Empirical Formula: $C_7H_{15}NO_3$
Molecular Weight: 161.20

Each CARNITOR® (Levocarnitine) Tablet contains 330 mg of levocarnitine and the inactive ingredients magnesium stearate, microcrystalline cellulose and povidone.

Each 118 mL container of the CARNITOR® (Levocarnitine) Oral Solution contains 1 g of levocarnitine/10 mL. Also contains: Artificial Cherry Flavor, D,L-Malic Acid, Purified Water, Sucrose Syrup. Methylparaben NF and Propylparaben NF are added as preservatives. The pH is approximately 5.

CARNITOR® (Levocarnitine) Injection is a sterile aqueous solution containing 1 gram of levocarnitine per 5 mL ampoule and 500 mg of levocarnitine per 2.5 mL ampoule. The pH is adjusted to 6.0 - 6.5 with hydrochloric acid.

Clinical pharmacology
CARNITOR® (Levocarnitine) is a naturally occurring substance required in mammalian energy metabolism. It has been shown to facilitate long-chain fatty acid entry into cellular mitochondria, therefore delivering substrate for oxidation and subsequent energy production. Fatty acids are utilized as an energy substrate in all tissues except the brain. In skeletal and cardiac muscle they serve as major fuel. Primary systemic carnitine deficiency is characterized by low plasma, RBC, and/or tissue levels. It has not been possible to determine which symptoms are due to carnitine deficiency and which are due to the underlying organic acidemia, as symptoms of both abnormalities may be expected to improve with carnitine. The literature reports that carnitine can promote the excretion of excess organic or fatty acids in patients with defects in fatty acid metabolism and/or specific organic acidopathies that bioaccumulate acyl CoA esters.[1-6]

Secondary levocarnitine deficiency can be a consequence of inborn errors of metabolism. CARNITOR® may alleviate the metabolic abnormalities of patients with inborn errors that result in accumulation of toxic organic acids. Conditions for which this effect was demonstrated are: glutaric aciduria II, methyl malonic aciduria, propionic acidemia, and medium chain fatty acyl CoA dehydrogenase deficiency.[7,8] Autointoxication occurs in these patients due to the accumulations of acyl CoA compounds that disrupt intermediary metabolism. The subsequent hydrolysis of the acyl CoA compound to its free acid results in acidosis that can be life threatening. Levocarnitine clears the acyl CoA compound by formation of acyl carnitine which is quickly excreted. Levocarnitine deficiency is defined biochemically as abnormally low plasma levels of free carnitine (less than 20 µmol/L at one week post term) and may be associated with low tissue and/or urine levels. Further, this condition may be associated with a ratio of plasma ester/free levocarnitine levels greater than 0.4 or abnormally elevated levels of esterified levocarnitine in the urine. In premature infants and newborns, secondary deficiency is defined as plasma free levocarnitine levels below age related normal levels.

Bioavailability/Pharmacokinetics
In a relative bioavailability study in 15 healthy adult male volunteers CARNITOR® Tablets were found to be bio-equivalent to CARNITOR® Oral Solution. Following the administration of 1980 mg b.i.d., the maximum plasma concentration level (C_{max}) was 80 nmol/mL and the time to maximum concentration (T_{max}) occurred at 3.3 hours. There were no significant differences for AUC and urinary excretion observed between these two formulations.

In the same bioavailability study of 15 healthy adult males, CARNITOR® (Levocarnitine) Injection administered as a slow 3 minute bolus intravenous injection at a dose of 20 mg/kg showed that free levocarnitine plasma profiles are best fit by a two compartment model. Approximately 76% of free levocarnitine is eliminated in the urine. Using plasma levels uncorrected for endogenous levocarnitine, the mean distribution half life was 0.585 hours and the mean apparent terminal elimination half life was 17.4 hours following a single intravenous dose.

The absolute bioavailability of L-carnitine from CARNITOR® Tablets and Oral Solution was determined compared to the bioavailability of L-carnitine from CARNITOR® (Injection) intravenous in 15 healthy male volunteers. After correction for circulating endogenous levels of L-carnitine in the plasma, absolute bioavailability was 15.1% ± 5.3% for L-carnitine from CARNITOR® Tablets and 15.9% ± 4.9% from the Oral Solution.

Total body clearance of L-carnitine (Dose/AUC including endogenous baseline levels) was a mean of 4.00 L/hr. Endogenous baseline levels were not subtracted since total body clearance of L-carnitine does not distinguish between exogenous sources of L-carnitine and endogenously synthesized L-carnitine. Volume of distribution of the intravenously administered dose above baseline endogenous levels was calculated to be a mean of 29.0 L ± 7.1 L (approximately 0.39 L/kg) which is an underestimate of the true volume of distribution since plasma L-carnitine is known to equilibrate slowly with, for instance, muscle L-carnitine.

L-carnitine was not bound to plasma protein or albumin when tested at any concentration or with any species including the human.[9]

Metabolism and excretion
Five normal adult male volunteers, administered a dose of $[^3H$-methyl$]$-L-carnitine following 15 days of a high carnitine diet and additional carnitine supplement, excreted 58% to 65% of administered radioactive dose in 5 to 11 days in the urine and feces. Maximum concentration of $[^3H$-methyl$]$-L-carnitine in serum occurred from 2.0 to 4.5 hr after drug administration. Major metabolites found were trimethylamine N-oxide, primarily in urine (8% to 49% of the administered dose) and $[^3H]$-g-butyrobetaine, primarily in feces (0.44% to 45% of the administered dose). Urinary excretion of carnitine was 4% to 8% of the dose. Fecal excretion of total carnitine was less than 1% of total carnitine excretion.[10]

After attainment of steady state following 4 days of oral administration of L-carnitine with CARNITOR® Tablets (1980 mg q12h) or Oral Solution (2000 mg q12h) to 15 healthy male volunteers, urinary excretion of L-carnitine was a mean of 2107 and 2339 µmoles, respectively, equivalent to 8.6% and 9.4%, respectively, of the orally administered doses (uncorrected for endogenous urinary excretion). After a single intravenous dose (20 mg/kg) prior to multiple oral doses, urinary excretion of L-carnitine was 6974 µmoles, equivalent to 75.6% of the intravenously administered dose (uncorrected for endogenous urinary excretion).

Indications and usage
CARNITOR® (Levocarnitine) Tablets and Oral Solution are indicated in the treatment of primary systemic carnitine deficiency. In the reported cases, the clinical presentation consisted of recurrent episodes of Reye-like encephalopathy, hypoketotic hypoglycemia, and/or cardiomyopathy. Associated symptoms included hypotonia, muscle weakness and failure to thrive. A diagnosis of primary carnitine deficiency requires that serum, red cell and/or tissue carnitine levels be low and that the patient does not have a primary defect in fatty acid or organic acid oxidation (see Clinical Pharmacology). In some patients, particularly those presenting with cardiomyopathy, carnitine supplementation rapidly alleviated signs and symptoms. Treatment should include, in addition to carnitine, supportive and other therapy as indicated by the condition of the patient. CARNITOR® (Levocarnitine) Tablets and Oral Solution are also indicated for acute and chronic treatment of patients with an inborn error of metabolism that results in a secondary carnitine deficiency.

CARNITOR® (Levocarnitine) Injection is indicated for the acute and chronic treatment of patients with an inborn error of metabolism that results in secondary carnitine deficiency.

Contraindications
None known.

Warnings
None.

Precautions
General
CARNITOR® (Levocarnitine) Oral Solution is for oral/internal use only.
Not for parenteral use.

Gastrointestinal reactions may result from too rapid consumption of carnitine. CARNITOR® (Levocarnitine) Oral Solution may be consumed alone, or dissolved in drinks or other liquid foods to reduce taste fatigue. It should be consumed slowly and doses should be spaced evenly throughout the day to maximize tolerance.

Carcinogenesis, mutagenesis, impairment of fertility
Mutagenicity tests performed in *Salmonella typhimurium*, *Saccharomyces cerevisiae*, and *Schizosaccharomyces pombe* indicate that CARNITOR® (Levocarnitine) is not mutagenic. Long-term animal studies have not been conducted to evaluate the carcinogenicity of the compound.

Pregnancy
Pregnancy Category B
Reproductive studies have been performed in rats and rabbits at doses up to 3.8 times the human dose on the basis of surface area and have revealed no evidence of impaired fertility or harm to the fetus due to CARNITOR®. There are, however, no adequate and well controlled studies in pregnant women. Because animal reproduction studies are not always predictive of human response, this drug should be used during pregnancy only if clearly needed.

Nursing Mothers
It is not known whether this drug is excreted in human milk. Because many drugs are excreted in human milk, a decision should be made whether to discontinue nursing or to discontinue the drug, taking into account the importance of the drug to the mother.

Pediatric use
See Dosage and administration.

Adverse reactions
CARNITOR® (Levocarnitine) Oral Solution and Tablets.
Various mild gastrointestinal complaints have been reported during the long-term administration of oral L- or D,L-carnitine; these include transient nausea and vomiting, abdominal cramps, and diarrhea. Mild myasthenia has been described only in uremic patients receiving D,L-carnitine. Gastrointestinal adverse reactions with CARNITOR® (Levocarnitine) Oral Solution dissolved in liquids might be avoided by a slow consumption of the solution or by a greater dilution. Decreasing the dosage often diminishes or eliminates drug-related patient body odor or gastrointestinal symptoms when present. Tolerance should be monitored very closely during the first week of administration, and after any dosage increases.

Seizures have been reported to occur in patients with or without pre-existing seizure activity receiving either oral or intravenous levocarnitine. In patients with pre-existing seizure activity, an increase in seizure frequency and/or severity has been reported.

CARNITOR® (Levocarnitine) Injection.
Transient nausea and vomiting have been observed. Less frequent adverse reactions are body odor, nausea, and gastritis. An incidence for these reactions is difficult to estimate due to the confounding effects of the underlying pathology.

Seizures have been reported to occur in patients with or without pre-existing seizure activity receiving either oral or intravenous levocarnitine. In patients with pre-existing seizure activity, an increase in seizure frequency and/or severity has been reported.

Overdosage
There have been no reports of toxicity from carnitine overdosage. The oral LD_{50} of levocarnitine in mice is 19.2 g/kg. Carnitine may cause diarrhea. Overdosage should be treated with supportive care.

Dosage and administration
CARNITOR® (Levocarnitine) Tablets.
Adults: The recommended oral dosage for adults is 990 mg two or three times a day using the 330 mg tablets, depending on clinical response.

Infants and children: The recommended oral dosage for infants and children is between 50 and 100 mg/kg/day in divided doses, with a maximum of 3 g/day. Dosage should begin at 50 mg/kg/day. The exact dosage will depend on clinical response.

Monitoring should include periodic blood chemistries, vital signs, plasma carnitine concentrations and overall clinical condition.

CARNITOR® (Levocarnitine) Oral Solution.
For oral use only. **Not for parenteral use.**
Adults: The recommended dosage of levocarnitine is 1 to 3 g/day for a 50 kg subject, which is equivalent to 10 to 30 mL/day of CARNITOR® (Levocarnitine) Oral Solution. Higher doses should be administered only with caution and only where clinical and biochemical considerations make it seem likely that higher doses will be of benefit. Dosage should start at 1 g/day, (10 mL/day), and be increased slowly while assessing tolerance and therapeutic response. Monitoring should include periodic blood chemistries, vital signs, plasma carnitine concentrations, and overall clinical condition.

Infants and children: The recommended dosage of levocarnitine is 50 to 100 mg/kg/day, which is equivalent to 0.5 mL/kg/day CARNITOR® (Levocarnitine) Oral Solution. Higher doses should be administered only with caution and only where clinical and biochemical considerations make it seem likely that higher doses will be of benefit. Dosage should start at 50 mg/kg/day, and be increased slowly to a maximum of 3 g/day (30 mL/day) while assessing tolerance and therapeutic response. Monitoring should include periodic blood chemistries, vital signs, plasma carnitine concentrations, and overall clinical condition.

CARNITOR® (Levocarnitine) Oral Solution may be consumed alone or dissolved in drink or other liquid food. Doses should be spaced evenly throughout the day (every three or four hours) preferably during or following meals and should be consumed slowly in order to maximize tolerance.

CARNITOR® (Levocarnitine) Injection.
CARNITOR® Injection is administered intravenously. The recommended dose is 50 mg/kg given as a slow 2-3 minute bolus injection or by infusion. Often a loading dose is given in patients with severe metabolic crisis followed by an equivalent dose over the following 24 hours. It should be administered q3h or q4h, and never less than q6h either by infusion or by intravenous injection. All subsequent daily doses are recommended to be in the range of 50 mg/kg or as therapy may require. The highest dose administered has been 300 mg/kg.

It is recommended that a plasma carnitine level be obtained prior to beginning this parenteral therapy. Weekly and monthly monitoring is recommended as well. This monitoring should include blood chemistries, vital signs, plasma carnitine concentrations (the plasma free carnitine level should be between 35 and 60 micromoles/L) and overall clinical condition.

Parenteral drug products should be inspected visually for particulate matter and discoloration prior to administration, whenever solution and container permit.

Compatibility and Stability
Carnitor® Injection is compatible and stable when mixed in parenteral solutions of Sodium Chloride 0.9% or Lactated Ringer's in concentrations ranging from 250 mg/500 mL (0.5 mg/mL) to 4200 mg/500 mL (8.0 mg/mL) and stored at room temperature (25°C) for up to 24 hours in PVC plastic bags.

How supplied
CARNITOR® (Levocarnitine) Tablets are supplied as 330 mg tablets embossed with "CARNITOR ST" in individual blisters, packaged in boxes of 90 (NDC 54482-144-07). Store at controlled room temperature (25°C). See USP.

CARNITOR® (Levocarnitine) Oral Solution is supplied in 118 mL (4 FL. OZ.) multiple-unit plastic containers. The multiple-unit containers are packaged 24 per case (NDC 54482-145-08). Store at controlled room temperature (25°C). See USP.

CARNITOR® (Levocarnitine) Oral Solution is manufactured for Sigma-tau Pharmaceuticals, Inc. By: Alpharma USPD, Inc. Baltimore, MD 21244-2654 and/or Hi-Tech Pharmacal Co., Inc. Amityville, NY 11701.

CARNITOR® (Levocarnitine) Injection, 200 mg per 1 mL, is available in 5 mL single dose ampoules packaged 5 ampoules per carton (NDC 54482-146-09) and in 2.5 mL single dose ampoules packaged 5 ampoules per carton (NDC 54482-146-10). Made in Italy.

Store ampoules at controlled room temperature (25°C). See USP. Store in carton until their use to protect from light. Discard unused portion of an opened ampoule, as they contain no preservative.

Rx only

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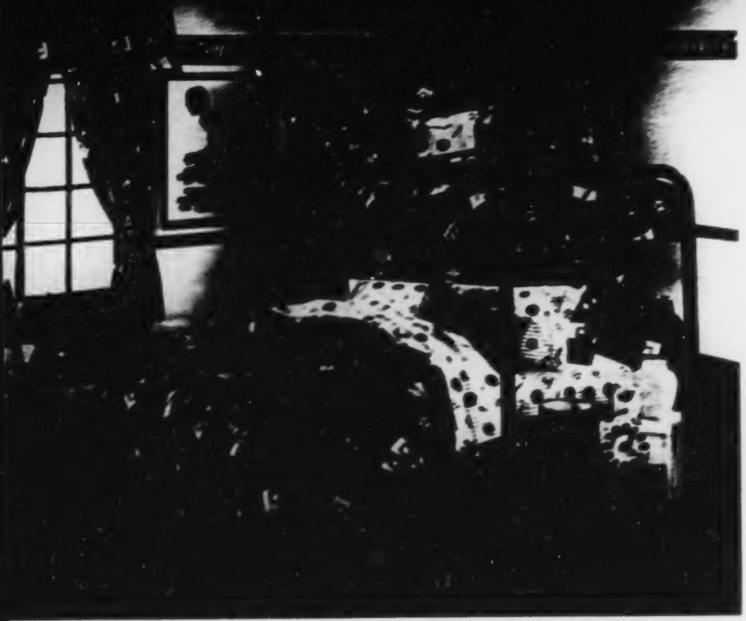

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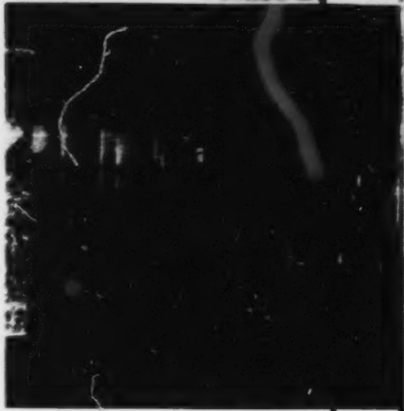

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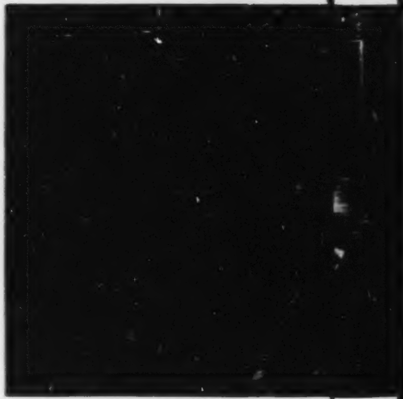

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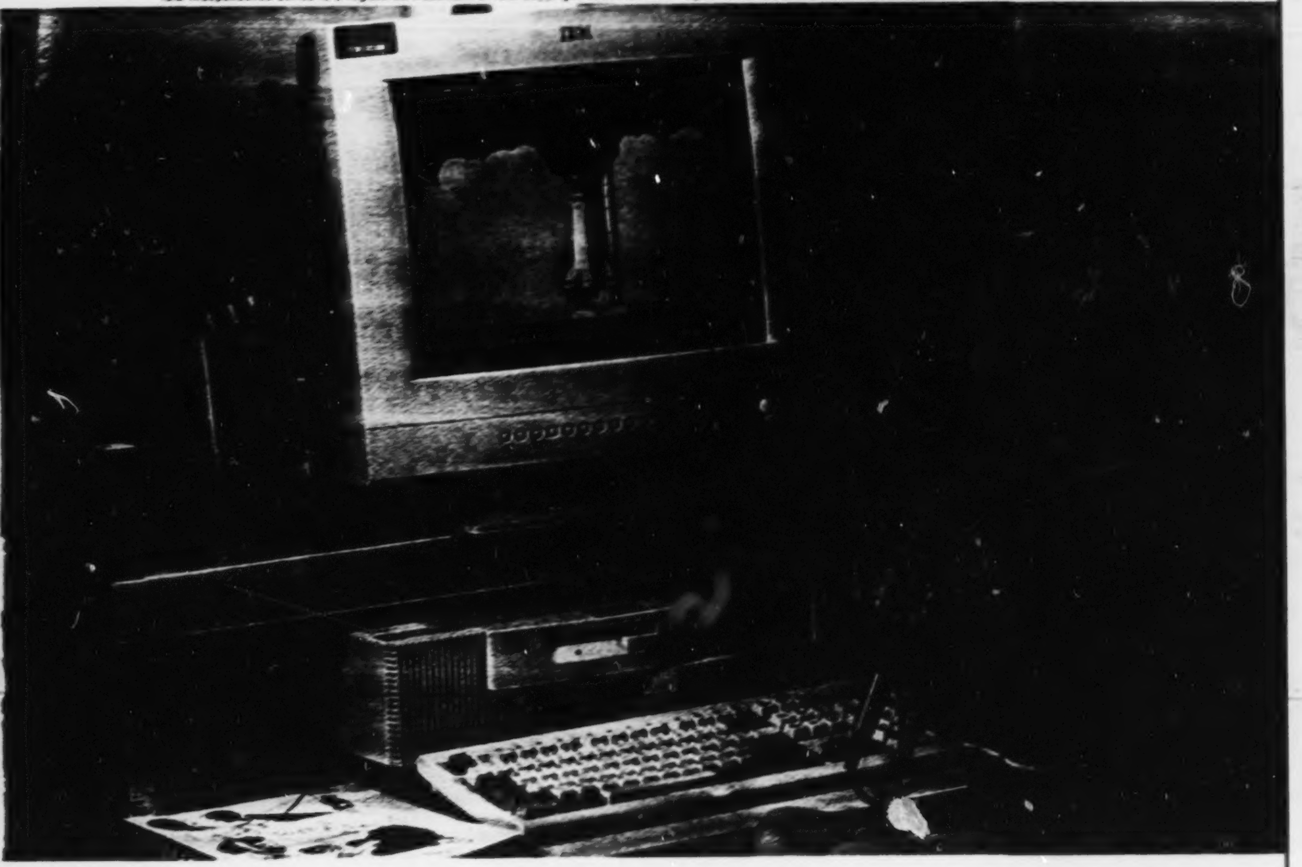

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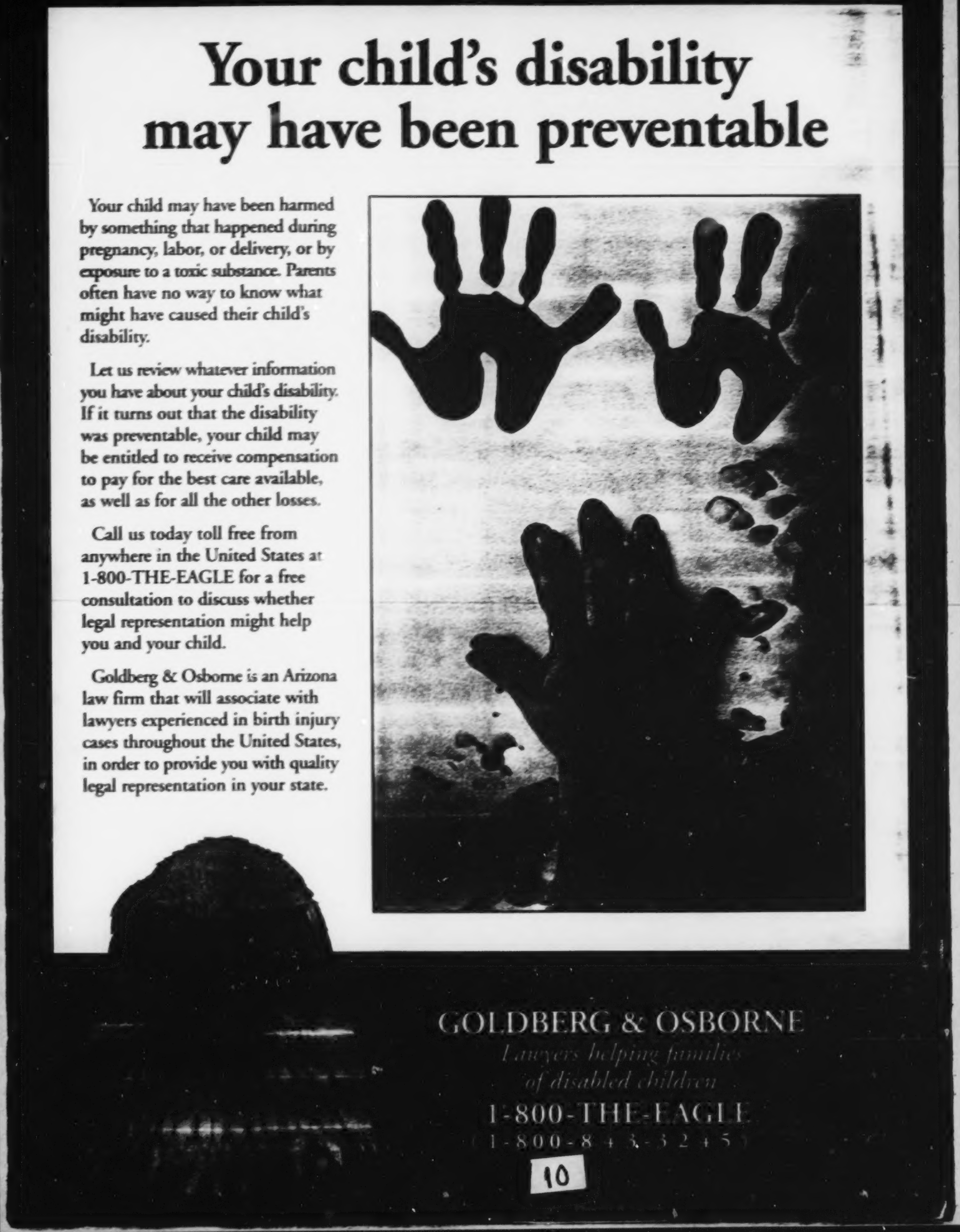

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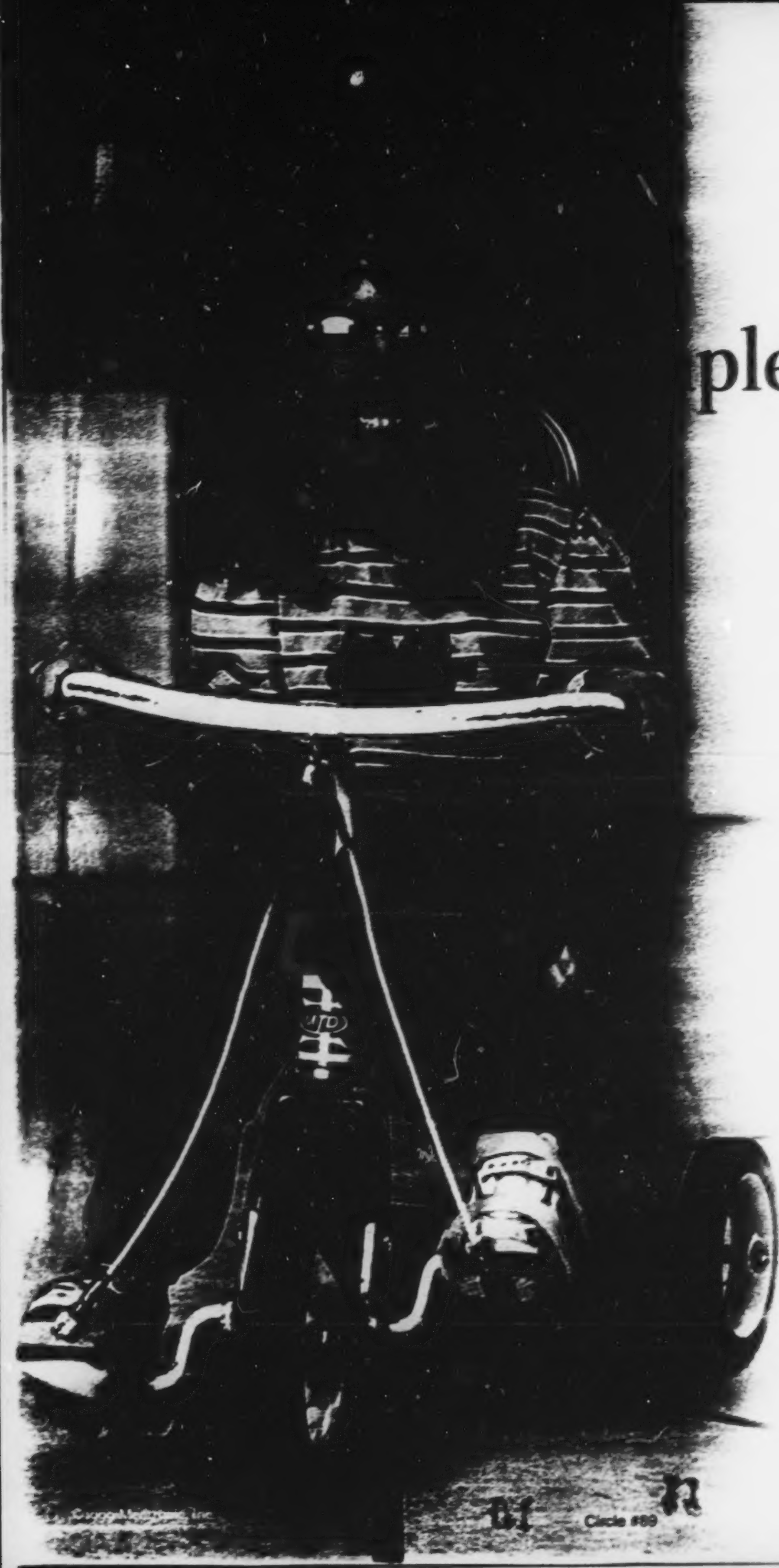

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EXCEPTIONAL
PARENT
Parenting your child or young adult with a disability or special healthcare needs

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A New Century Dawns

As I write these words, the last days of the old year, and old century, are dwindling away. It is at this time everyone has the urge to take stock and look back over the past. While it is always important to remember the past, knowing how to find your way into the future is just as vital, and never more so than now! While putting together this year's Resource Guide, we tried to keep in mind both of these perspectives.

This year we have included some of the same information that has proven helpful to our readers in their role as partners in all the decisions made for their child as well as adding some new features.

We have updated all our listings: from accessibility in amusement parks nationwide, to national and international resources for specific disabilities, as well as those for the various federal and state agencies overseeing the programs that are the right of every child with a disability. Some new features include a selection of Colleges and Universities for Students with Learning Disabilities and a listing of hospitals from the National Association of Children's Hospitals and Related Institutions (NACHRI), advocacy resources, and rating managed care organizations (MCOs).

Advocacy

Families often have some difficulty in negotiating the various service providers and in protecting their child's rights. Unfortunately, an alarming number of city and state agencies often dare families to demand their due, causing the family to face lengthy and costly legal battles when their child needs services immediately. This year we have added information on two advocacy groups that can help you to manage these dilemmas: the National Association of Protection and Advocacy Systems (NAPAS) and the Developmental Disability Councils, which are present in most states.

Health Services-MCOs

The most important change in the delivery of medical services is the development of managed care organizations (MCOs). They are now the major vehicles for covering health costs, though consumers usually have no say in choosing them. As a result, MCOs have become the focus of continuous complaint and confusion. In this issue, Fern Potvin reports on how some of the largest MCOs throughout the country have been rated according to the National Committee for Quality Assurance, which has developed a system of performance measures and accreditation. Also included in this issue is a state-by-state listing from Family Voices of their Coordinators serving as advocates for families in their states who are dealing with insurance issues.

EP on-line

Use of the Internet is now such an integral part of our lives that we think nothing of turning to it first for information. This raises some concerns as to the quality of the information. Our Internet Projects Manager, Vanessa Ira has included some pointers in this issue on what users should expect on a Web site. Our own on-line presence at http://www.eparent.com contains the same quality information that you will find in print. As in our magazine, we would like the Web site to be a reflection of your needs. Please continue to send your suggestions for how we can "build a better Web site" via e-mail to Vanessa at: vieprnt@concentric.net or call (800) EPARENT, ext. 213

With gratitude

We are very lucky to have many caring individuals—more than we can name here—share their talents with us, both as authors and as advisors to our publication, and we wish to express our gratitude and look forward to their continued support in the coming years. Joe Valenzano and our staff here at EP, in editorial, circulation, and advertising have put forth a tremendous effort in supporting our mission. I would like to recognize and thank for their contributions: Laura Battaglia, Glenn Collucci, Anthony Cuigini, Doris DeFina, J.M. DellaValle, Francois Dufresne, Dennis Dusevic, Julie Hacker, Vanessa Ira, Gale Jurasek, Dolores Kinley, Mike Longobardi, Bridget Lyne, Kerry Pianoforte, Fern Potvin, Ann Weber, and Karen Weber, as well as our EP Library staff and our sales force.

Pictured are some of EP's staff and friends: Front (l-r): Bob Molica, J.M. DellaValle, Dennis Dusevic, Joe Miller, Ann Weber, Kerry Pianoforte, Julie Hacker with Brielle Hacker, Blucher Chacon. Second row (l-r) Bridget Lyne, Ron Richards, Gale Jurasek, Fern Potvin, Lauren Agoratus, Amy Koval, Esther Schleifer, Andrew Zerias, Joe Valenzano, Dolores Kinley, Doris DeFina, Laura Battaglia, Glenn Collucci (directly behind Laura), Mike Manginello, Mike Longobardi, and Max Schleifer. (Not pictured: Anthony Cuigini, Vanessa Ira, Karen Weber, Francois Dufresne.)

Come join us in Atlanta

EP will co-sponsor The World Congress & Exposition on Disabilities (WCD), November 10-12, 2000 in Atlanta, Georgia. We invite individuals who have disabilities and their families, along with leading experts on disability-related fields from around the world, to come together at this forum to share their knowledge and experience.

The new year before us holds great promise, waiting to be filled with accomplishments and improvements as we cross the threshold into the new century. We hope EP can continue to be a useful source of information, and through contributions from our readers, a source of inspiration. **EP**

Best wishes for a bright and joyous New Year from everyone at EP!

—*Maxwell J. Schleifer, Ph.D.*
Editor-in-Chief

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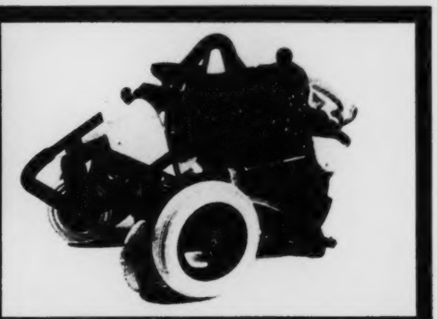

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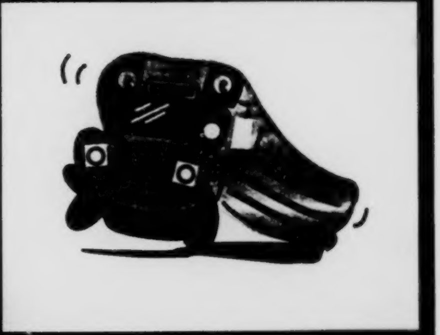

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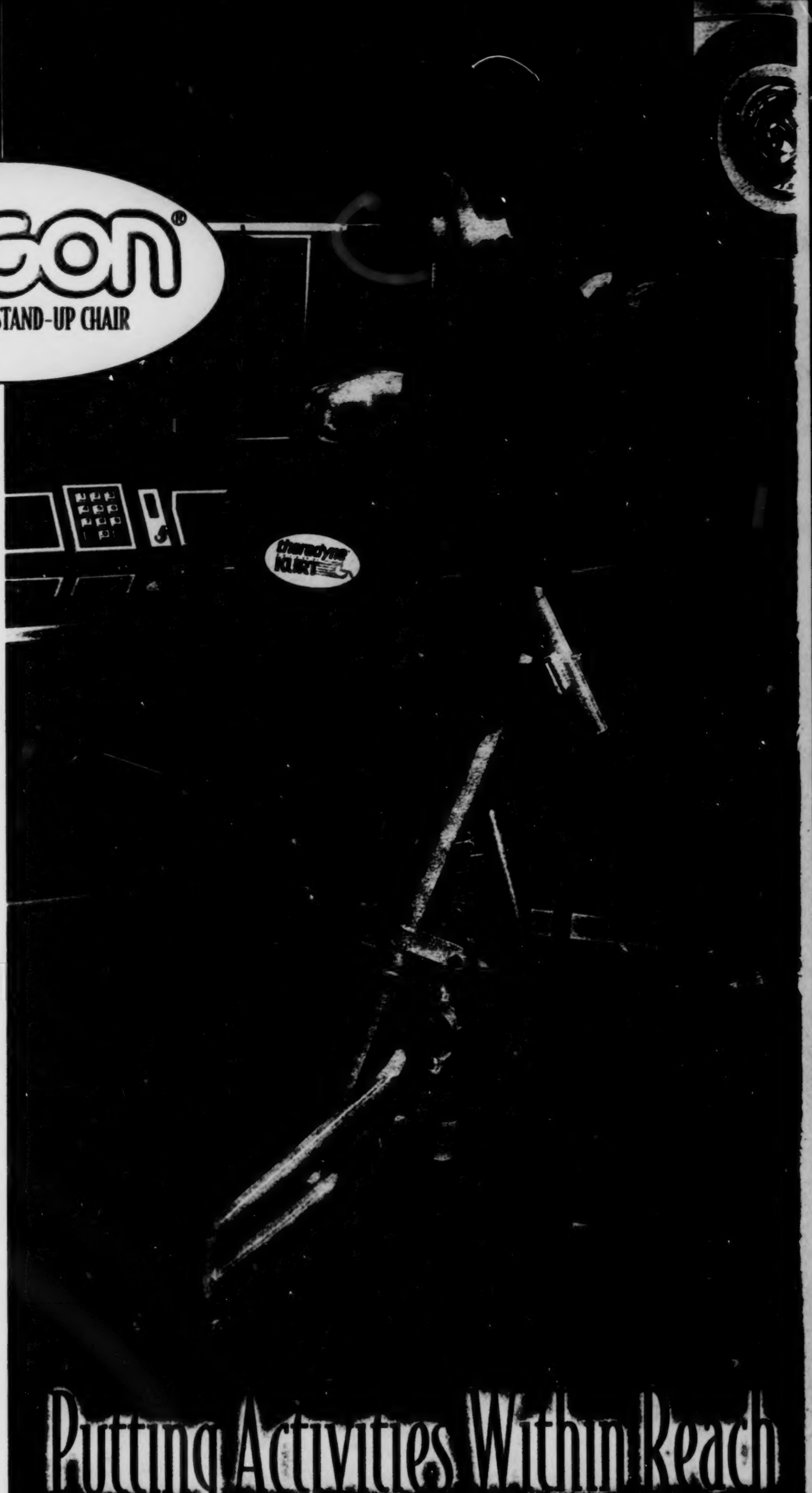

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INDICATIONS AND USAGE

Diastat is a gel formulation of diazepam intended for rectal administration in the management of selected, refractory, patients with epilepsy, on stable regimens of AEDs, who require intermittent use of diazepam to control bouts of increased seizure activity.

Evidence to support the use of Diastat was adduced in two controlled trials that enrolled patients with partial onset or generalized convulsive seizures who were identified jointly by their caregivers and physicians as suffering intermittent and periodic episodes of markedly increased seizure activity, sometimes heralded by non-convulsive symptoms, that for the individual patient were characteristic and were deemed by the prescriber to be of a kind for which a benzodiazepine would ordinarily be administered acutely. Although these clusters or bouts of seizures differed among patients, for any individual patient the clusters of seizure activity were not only stereotypic but were judged by those conducting and participating in these studies to be distinguishable from other seizures suffered by that patient. The conclusion that a patient experienced such unique episodes of seizure activity was based on historical information.

CONTRAINDICATIONS

Diastat is contraindicated in patients with a known hypersensitivity to diazepam. Diastat may be used in patients with open angle glaucoma who are receiving appropriate therapy but is contraindicated in acute narrow angle glaucoma.

WARNINGS

General

Diastat should only be administered by caregivers who in the opinion of the prescribing physician 1) are able to distinguish the distinct cluster of seizures (and/or the events presumed to herald their onset) from the patient's ordinary seizure activity, 2) have been instructed and judged to be competent to administer the treatment rectally, 3) understand explicitly which seizure manifestations may or may not be treated with Diastat, and 4) are able to monitor the clinical response and recognize when that response is such that immediate professional medical evaluation is required.

CNS Depression

Because Diastat produces CNS depression, patients receiving this drug who are otherwise capable and qualified to do so should be cautioned against engaging in hazardous occupations requiring mental alertness, such as operating machinery, driving a motor vehicle, or riding a bicycle until they have completely returned to their level of baseline functioning.

Pregnancy Risks

Animal Findings: Diazepam has been shown to be teratogenic in mice and hamsters when given orally at single doses of 100 mg/kg or greater (approximately eight times the maximum recommended human dose [MRHD=1 mg/kg/day] or greater on a mg/m^2 basis).

General Concerns and Considerations About Anticonvulsants: Reports suggest an association between the use of anticonvulsant drugs by women with epilepsy and an elevated incidence of birth defects in children born to these women.

General Concerns About Benzodiazepines: An increased risk of congenital malformations associated with the use of benzodiazepine drugs has been suggested in several studies. There may also be non-teratogenic risks associated with the use of benzodiazepines during pregnancy. There have been reports of neonatal flaccidity, respiratory and feeding difficulties, and hypothermia in children born to mothers who have been receiving benzodiazepines late in pregnancy. In addition, children born to mothers receiving benzodiazepines on a regular basis late in pregnancy may be at some risk of experiencing withdrawal symptoms during the postnatal period.

Advice Regarding the Use of Diastat in Women of Childbearing Potential: In general, the use of Diastat in women of childbearing potential, and more specifically during known pregnancy, should be considered only when the clinical situation warrants the risk to the fetus.

The specific considerations addressed above regarding the use of anticonvulsants in epileptic women of childbearing potential should be weighed in treating or counseling these women.

Because of experience with other members of the benzodiazepine class, Diastat is assumed to be capable of causing an increased risk of congenital abnormalities when administered to a pregnant woman during the first trimester. The possibility that a woman of childbearing potential may be pregnant at the time of institution of therapy should be considered. If this drug is used during pregnancy, or if the patient becomes pregnant while taking this drug, the patient should be apprised of the potential hazard to the fetus. Patients should also be advised that if they become pregnant during therapy or intend to become pregnant they should communicate with their physician about the desirability of discontinuing the drug.

Withdrawal Symptoms

Withdrawal symptoms of the barbiturate type have occurred after the discontinuation of regular use of benzodiazepines.

Chronic Use

Diastat is not recommended for chronic, daily use as an anticonvulsant because of the potential for development of tolerance to diazepam. Chronic daily use of diazepam may increase the frequency and/or severity of tonic clonic seizures, requiring an increase in the dosage of standard anticonvulsant medication. In such cases, abrupt withdrawal of chronic diazepam may also be associated with a temporary increase in the frequency and/or severity of seizures.

Use in Patients with Petit Mal Status

Tonic *status epilepticus* has been precipitated in patients treated with IV diazepam for petit mal status or petit mal variant status.

PRECAUTIONS

Caution in Renally Impaired Patients

Caution should be exercised in the administration of the drug to patients with impaired renal function.

Caution in Hepatically Impaired Patients

Concomitant liver disease is known to decrease the clearance of diazepam. Therefore, Diastat should be used with caution in patients with liver disease.

Use in Pediatrics

The controlled trials demonstrating the effectiveness of Diastat included children two years of age and older.

Use in Patients with Compromised Respiratory Function

Diastat should be used with caution in patients with compromised respiratory function related to a concurrent disease process (e.g., asthma, pneumonia) or neurologic damage.

Use in Elderly

In elderly patients Diastat should be used with caution.

Information to be Communicated by the Prescriber to the Caregiver

Prescribers are strongly advised to take all reasonable steps to ensure that caregivers fully understand their role and obligations vis a vis the administration of Diastat to individuals in their care.

Interference With Cognitive and Motor Performance: Because benzodiazepines have the potential to impair judgment, thinking, or motor skills, patients should be cautioned about operating hazardous machinery, including automobiles, until they are reasonably certain that Diastat therapy does not affect them adversely.

Pregnancy: Patients should be advised to notify their physician if they become pregnant or intend to become pregnant during therapy with Diastat.

Nursing: Patients should be advised not to breast-feed for an appropriate period of time after receiving treatment with Diastat.

Concomitant Medication

The potential for a synergistic CNS-depressant effect when used simultaneously with alcohol or other CNS-depressants must be considered by the prescribing physician, and appropriate recommendations made to the patient and/or caregiver.

Drug Interactions

If Diastat is to be combined with other psychotropic agents or other CNS depressants, careful consideration should be given to the pharmacology of the agents to be employed—particularly with known compounds which may potentiate the action of diazepam, such as phenothiazines, narcotics, barbiturates, MAO inhibitors and other antidepressants.

The clearance of diazepam and certain other benzodiazepines can be delayed in association with cimetidine administration. Valproate may potentiate the CNS-depressant effects of diazepam.

As with all drugs, the potential for interaction by a variety of mechanisms is a possibility.

Effect of Other Drugs On Diazepam Metabolism: Potential interactions may occur when diazepam is given concurrently with agents that affect CYP2C19 and CYP3A4 activity. Potential inhibitors of CYP2C19 (e.g., cimetidine, quinidine, and tranylcypromine) and CYP3A4 (e.g., ketoconazole, troleandomycin, and clotrimazole) could decrease the rate of diazepam elimination, while inducers of CYP2C19 (e.g., rifampin) and CYP3A4 (e.g., carbamazepine, phenytoin, dexamethasone and phenobarbital) could increase the rate of elimination of diazepam.

Effect of Diazepam On the Metabolism of Other Drugs: Diazepam may interfere with the metabolism of drugs which are substrates for CYP2C19, (e.g. omeprazole, propranolol, and imipramine) and CYP3A4 (e.g. cyclosporine, paclitaxel, terfenadine, theophylline, and warfarin) leading to a potential drug-drug interaction.

Carcinogenesis, Mutagenesis, Impairment of Fertility

In studies in which mice and rats were administered diazepam in the diet at a dose of 75 mg/kg/day (approximately six and 12 times, respectively, the maximum recommended human dose [MRHD=1 mg/kg/day] on a mg/m^2 basis) for 80 and 104 weeks, respectively, an increased incidence of liver tumors was observed in males of both species. The data currently available are inadequate to determine the mutagenic potential of diazepam. Reproduction studies in rats showed decreases in the number of pregnancies and in the number of surviving offspring following administration of an oral dose of 100 mg/kg/day (approximately 16 times the MRHD on a mg/m^2 basis).

Labor and Delivery

Diastat is not recommended for obstetrical use.

Nursing Mothers

Patients should be advised not to breast-feed for an appropriate period of time after receiving treatment with Diastat.

ADVERSE REACTIONS

Diastat adverse event data were collected from double-blind, placebo-controlled studies and open-label studies. The majority of adverse events were mild to moderate in severity and transient in nature.

Two patients who received Diastat died seven to 15 weeks following treatment; neither of these deaths was deemed related to Diastat.

The most frequent adverse event reported to be related to Diastat in the two double-blind, placebo-controlled studies was somnolence (23%). Less frequent adverse events were dizziness, headache, pain, abdominal pain, nervousness, vasodilatation, diarrhea, ataxia, euphoria, incoordination, asthma, rhinitis, and rash, which occurred in approximately 2-5% of patients.

Approximately 1.4% of the 573 patients who received Diastat in clinical trials of epilepsy discontinued treatment because of an adverse event. The adverse event most frequently associated with discontinuation (occurring in three patients) was somnolence. Other adverse events most commonly associated with discontinuation and occurring in two patients were hypoventilation and rash. Adverse events occurring in one patient were asthenia, hyperkinesia, incoordination, vasodilitation and urticaria. These events were judged to be related to Diastat.

In the two domestic double-blind, placebo-controlled, parallel-group studies, the proportion of patients who discontinued treatment because of adverse events was 2% for the group treated with Diastat, versus 2% for the placebo group. In the Diastat group, the adverse events considered the primary reason for discontinuation were different in the two patients who discontinued treatment; one discontinued due to rash and one discontinued due to lethargy. The primary reason for discontinuation in the patients treated with placebo was lack of effect.

Adverse Event Incidence in Controlled Clinical Trials

Table 1 lists treatment-emergent signs and symptoms that occurred in > 1% of patients enrolled in parallel-group, placebo-controlled trials and were numerically more common in the Diastat group. Adverse events were usually mild or moderate in intensity.

The prescriber should be aware that these figures, obtained when Diastat was added to concurrent antiepileptic drug therapy, cannot be used to predict the frequency of adverse events in the course of usual medical practice when patient characteristics and other factors may differ from those prevailing during clinical studies. Similarly, the cited frequencies cannot be directly compared with figures obtained from other clinical investigations involving different treatments, uses, or investigators. An inspection of these frequencies, however, does provide the prescribing physician with one basis to estimate the relative contribution of drug and non-drug factors to the adverse event incidences in the population studied.

TABLE 1: Treatment-Emergent Signs And Symptoms That Occurred In > 1% Of Patients Enrolled In Parallel-Group, Placebo-Controlled Trials And Were Numerically More Common In The Diastat Group

Body System	COSTART Term	Diastat N = 101 %	Placebo N = 104 %
Body As A Whole	Headache	5%	4%
Cardiovascular	Vasodilatation	2%	0%
Digestive	Diarrhea	4%	<1%
Nervous	Ataxia	3%	<1%
	Dizziness	3%	2%
	Euphoria	3%	0%
	Incoordination	3%	0%
	Somnolence	23%	8%
Respiratory	Asthma	2%	0%
Skin and Appendages	Rash	3%	0%

Other events reported by 1% or more of patients treated in controlled trials but equally or more frequent in the placebo group than in the Diastat group were abdominal pain, pain, nervousness, and rhinitis. Other events reported by fewer than 1% of patients were infection, anorexia, vomiting, anemia, lymphadenopathy, grand mal convulsion, hyperkinesia, cough increased, pruritus, sweating, mydriasis, and urinary tract infection.

The pattern of adverse events was similar for different age, race and gender groups.

Other Adverse Events Observed During All Clinical Trials: Diastat has been administered to 573 patients with epilepsy during all clinical trials, only some of which were placebo-controlled. During these trials, all adverse events were recorded by the clinical investigators using terminology of their own choosing. To provide a meaningful estimate of the proportion of individuals having adverse events, similar types of events were grouped into a smaller number of standardized categories using modified COSTART dictionary terminology. These categories are used in the

listing below. All of the events listed below occurred in at least 1% of the 573 individuals exposed to Diastat. All reported events are included except those already listed above, events unlikely to be drug-related, and those too general to be informative. Events are included without regard to determination of a causal relationship to diazepam.

BODY AS A WHOLE: Asthenia

CARDIOVASCULAR: Hypotension, vasodilation

NERVOUS: Agitation, confusion, convulsion, dysarthria, emotional lability, speech disorder, thinking abnormal, vertigo

RESPIRATORY: Hiccup

The following infrequent adverse events were not seen with Diastat but have been reported previously with diazepam use: depression, slurred speech, syncope, constipation, changes in libido, urinary retention, bradycardia, cardiovascular collapse, nystagmus, urticaria, neutropenia and jaundice.

Paradoxical reactions such as acute hyperexcited states, anxiety, hallucinations, increased muscle spasticity, insomnia, rage, sleep disturbances and stimulation have been reported with diazepam; should these occur, use of Diastat should be discontinued.

DRUG ABUSE AND DEPENDENCE

Diazepam is a Schedule IV controlled substance and can produce drug dependence. It is recommended that patients be treated with Diastat no more frequently than every five days and no more than five times per month.

OVERDOSAGE

Flumazenil is intended as an adjunct to, not as a substitute for, proper management of benzodiazepine overdose. Patients treated with flumazenil should be monitored for resedation, respiratory depression and other residual benzodiazepine effects for an appropriate period after treatment.

The prescriber should be aware of a risk of seizure in association with flumazenil treatment, particularly in long-term benzodiazepine users and in cyclic antidepressant overdose.

DOSAGE AND ADMINISTRATION

(see Also Patient/Caregiver Package Insert)

A decision to prescribe Diastat involves more than the diagnosis and the selection of the correct dose for the patient.

First, the prescriber must be convinced from historical reports and/or personal observations that the patient exhibits the characteristic identifiable seizure cluster that can be distinguished from the patient's usual seizure activity by the caregiver who will be responsible for administering Diastat.

Second, because Diastat is only intended for adjunctive use, the prescriber must ensure that the patient is receiving an optimal regimen of standard anti-epileptic drug treatment and is, nevertheless, continuing to experience these characteristic episodes.

Third, because a non-health professional will be obliged to identify episodes suitable for treatment, make the decision to administer treatment upon that identification, administer the drug, monitor the patient, and assess the adequacy of the response to treatment, a major component of the prescribing process involves the necessary instruction of this individual.

Fourth, the prescriber and caregiver must have a common understanding of what is and is not an episode of seizures that is appropriate for treatment, the timing of administration in relation to the onset of the episode, the mechanics of administering the drug, how and what to observe following administration, and what would constitute an outcome requiring immediate and direct medical attention.

Calculating Prescribed Dose

The Diastat dose should be individualized for maximum beneficial effect. The recommended dose of Diastat is 0.2-0.5 mg/kg depending on age. See the dosing table for specific recommendations.

Age (years)	Recommended Dose
2 through 5	0.5 mg/kg
6 through 11	0.3 mg/kg
12 and older	0.2 mg/kg

Because Diastat is provided in fixed, unit-doses of 5, 10, 15 and 20 mg, the prescribed dose is obtained by rounding upward to the next available dose. The following table provides acceptable weight ranges for each dose and age category, such that patients will receive between 90% and 180% of the calculated recommended dose. The safety of this strategy has been established in clinical trials.

2 - 5 Years 0.5 mg/kg		6 - 11 Years 0.3 mg/kg		12+ Years 0.2 mg/kg	
Weight (kg)	Dose (mg)	Weight (kg)	Dose (mg)	Weight (kg)	Dose (mg)
6 to 11	5	10 to 18	5	14 to 27	5
12 to 22	10	19 to 37	10	28 to 50	10
23 to 33	15	38 to 55	15	51 to 75	15
34 to 44	20	56 to 74	20	76 to 111	20

In elderly and debilitated patients, it is recommended that the dosage be adjusted downward to reduce the likelihood of ataxia or oversedation.

A 2.5 mg dose is available for use as a supplemental dose. This dose may be prescribed at the discretion of the physician for patients who require more precise dose titration than is achieved using one of the four standard doses provided. The 2.5 mg dose may also be used as a partial replacement dose for patients who may expel a portion of the first dose.

Additional Dose

The prescriber may wish to prescribe a second dose of Diastat. A second dose, when required, may be given 4-12 hours after the first dose.

Treatment Frequency

It is recommended that Diastat be used to treat no more than five episodes per month and no more than one episode every five days.

CAUTION: Federal law prohibits dispensing without prescription.

CAUTION: Federal law prohibits the transfer of this drug to any person other than the patient for whom it was prescribed.

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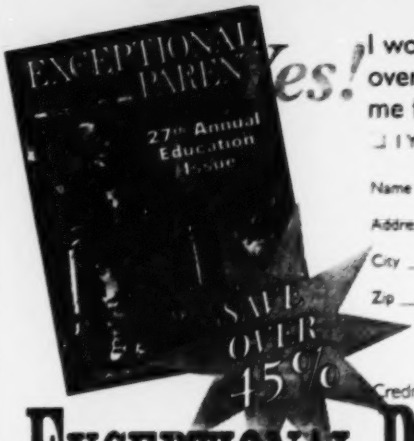

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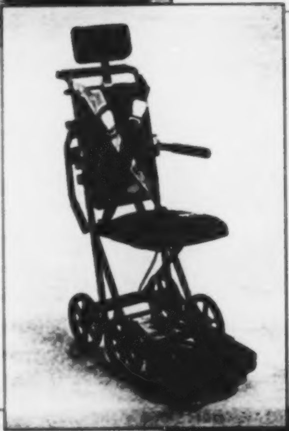

Columbia Medical, founder, Michael Caan, (left) is the inventor of the AisleMaster. The device (center & bottom) transports people with mobility-related disabilities on aircraft as well as on ships, trains and buses.

As a scientist for NASA geophysical studies, Michael Caan's work allowed him to learn about the physical forces on our planet. It was little wonder that after leaving NASA, he decided to put his knowledge of physics to work by helping people safely overcome physical limitations. He started his business, Columbia Medical Manufacturing Corporation, by making safety products in the garage of the suburban California home he shares with his wife and two daughters.

When the ADA (The Americans with Disabilities Act) and the Air Carrier Access Act made accommodating passengers with disabilities an important consideration for air carriers, Caan saw a need that would have to be filled. Airlines had to find a safe, economical, and comfortable way to board and transport people who use mobility devices. Cruise ships and trains would also be affected.

Designing the right type of chair was a challenge with conflicting requirements for Caan and his company, which had grown to include several other design professionals. "The chair had to be lightweight to make it easy to lift, yet strong enough to hold heavy users. It also had to be compact enough to fit on an aircraft and comfortable for the user. In addition, the chair had to be simple to use, and affordable for the airlines to purchase," explains Caan.

In an effort to achieve these standards, Caan and his team consulted with a number of commercial airlines. Caan's first customer was American Airlines. "They were particularly receptive of first samples, while giving us very knowledgeable input," he recalls.

After experimenting with many different types of products, Caan came up with the AisleMaster Boarding Chair. Weighing in at only 33 pounds, with a 15 inch-wide wheelbase, the wheelchair is compact and versatile. Unique features include an adjustable headrest; crisscrossing, color-coded body straps to hold the passenger securely and comfortably; and thigh and ankle straps. In an effort to reduce risks and make boarding easier, the AisleMaster Chair's headrest lowers, the armrests flip up, and the seat acts as a sliding board.

Columbia Medical now makes both boarding and on-board chairs. There are currently three types of chairs in use by commercial airlines:

1) Terminal chairs used within airport terminals.
2) Boarding wheelchairs, which are often needed to transport passengers up stairs and down narrow aisles of a plane.
3) On-board chairs for larger aircraft, used for evacuations or to get passengers to the lavatory during a flight.

In addition to the 15 inch-wide model, Columbia has also designed a 12-inch version of the AisleMaster Chair for use on commuter airlines and buses where extra narrow aisles exist. For passengers with disabilities, this opened up a new world of travel opportunity. "Previously, passengers had to be physically hand-carried up and down the steps. This evolution is significant given the enormous growth of 'feeder' airports using regional airlines feeding into "hubs" for nationwide carriers," explains Caan.

Today, the AisleMaster is sold to over 60 airlines and has been purchased individually by actor Christopher Reeve, and by President Clinton for use aboard Air Force One when he injured his knee a few years ago. Caan and his staff at Columbia Medical also put their minds to designing more "down to earth" products including bath seats, commodes, and car seats, continuing to push the limits of accessible design for people with disabilities of all ages.

Travelers should check with their airlines in advance to make sure the AisleMaster will be available at the departure gate. **EP**

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Circle #19

PUBLISHERS LETTER

The Power of Parent Persistence

When we think of a hero, we often think of a person who is larger than life. Heroes, however, do walk among us in everyday life. I would like to tell you about one who is very much a part of the Exceptional Parent family: Julie Venners Hacker, our associate publisher. She has been selected as the recipient of a Joseph P. Kennedy, Jr. Fellowship in Public Policy. Julie has demonstrated what I like to call the Power of Parent Persistence. On January 1, 2000, Julie will begin the one-year fellowship in Washington, D.C. There she will continue to learn and grow, and acquire new skills in advocacy on behalf of those with disabilities. For Julie, and for Exceptional Parent, this is a tremendous honor and we are very proud of what she has accomplished and profoundly grateful that she has been such an integral part of the Exceptional Parent family. We know that she will continue to be successful and that she will make a significant contribution in the lives people with disabilities.

JULIE VENNERS HACKER

As Julie accepts the heartfelt congratulations of all those who wish her well and prepares to take on her new responsibilities, I would like to share some perspectives that are constant reminders of the journey that has led to this outstanding achievement.

I first met Julie at a National Organization for Rare Disorders (NORD) Conference in Dallas, Texas in 1996. With her was her daughter, Brielle, then 2 years old, who had been diagnosed with mitochondrial myopathy. Julie had come to the NORD conference to gain knowledge and gather support to help her in dealing with her daughter's disability. What struck me immediately about Julie was her energy, devotion, and commitment. And, I was captivated by Brielle; though her disease tired her out much of the time, her bright blue eyes were always shining and she could always muster a smile that melted your heart.

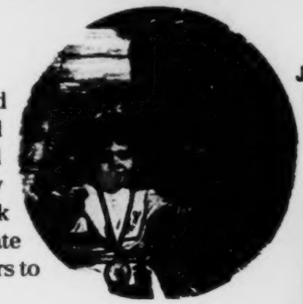
SAY CHEESE! BRIELLE HACKER, NOW 5½, HAS COME A LONG WAY FROM THE FRAIL CHILD SHE ONCE WAS.

A story to share

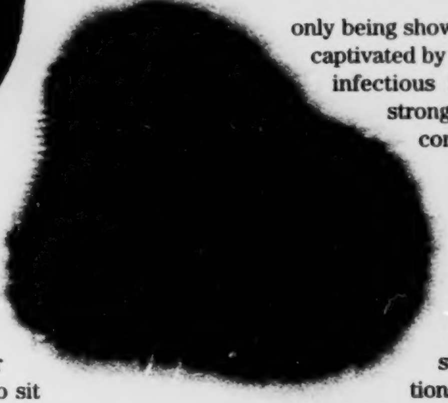
Julie told me how little was known about mitochondrial myopathy and how she wanted do something about that. She had already created her own non-profit foundation, the Juvenile Undiagnosed Mitochondrial Problems (J.U.M.P.) Foundation to help raise awareness and fund research into this mysterious disease. She also told me about Brielle and her condition. In 1996, Brielle's medical prognosis was not good. Mitochondrial myopathy is a hereditary disease in which the mitochondria (the powerhouse of the cells in our bodies) do not produce enough adenosine triosphate (ATP), which gives the body its energy.

Some leading neurologists told Julie that Brielle would never walk and would always have severe motor and intellectual delays. As an infant, Brielle could not eat solid foods and Julie was told that her daughter would need to be tube fed. But Julie was unwilling to accept that without a fight. Instead, with incredible patience, love,and dedication, she sat for hours on end holding and feeding Brielle the only thing she would eat—cream from those small containers used for coffee. Brielle began gaining strength this way and has not needed a tube. Eventually, when it was discovered that she had carnitine deficiency, Brielle began receiving medication which dramatically improved her condition.

I was resolved to have Julie tell her story in print—and she did. The article in our May 1997 issue served as the introduction to Exceptional Parent's three-part educational series on mitochondrial and metabolic disorders, which Julie helped coordinate. This special report served to increase awareness, among physicians and parents alike, of this pervasive and debilitating condition. The educational



Julie (below with her daughter) founded the non-profit J.U.M.P. to raise awareness for mitochondrial myopathy. Champion cyclist, Greg LeMond, (left) who also has the disease, agreed to be J.U.M.P.'s spokesperson. Here he holds Brielle on a trike.



series was also reproduced into two monographs and distributed to physicians and families internationally. Now in its third printing, this work has the potential to educate the next generation of doctors to be alert for this disorder.

Making a difference

This dedication to helping others prompted me to invite Julie to come to work with us at Exceptional Parent. I wanted this person, who had displayed such courage and dignity, to become part of the EP family. For her, however, it was not a simple transition or corporate move. Julie is the sole caregiver for her daughter, who then was nonverbal, frail, barely able to sit upright or eat solid foods, and had to be carried everywhere. She would have to find new support systems and make new friends. Making this move also meant that Julie had to negotiate with a different early intervention and school system, ones which did not offer many of the services that Brielle received in Michigan. But Julie wanted to join Exceptional Parent because, as she so often reminded us, she "wanted to make a difference." With the same resolve she had always shown, Julie uprooted herself from familiar surroundings and moved with Brielle from Michigan to New Jersey.

Julie did make a new life for herself and Brielle. All of her friends and colleagues here at the magazine have watched, with concern, anxiety, amazement, and pride as, day by day, Julie and Brielle did battle with her condition. We have witnessed Brielle grow stronger, from a small child with little muscle tone who would not eat, to an active little girl who now feeds herself. It was a source of great joy when Brielle finally was able to finish a plate of spaghetti! But nothing tops watching her today as she walks (but mostly runs!), albeit with the assistance of some specially designed braces for her legs. We were all delighted the day Julie told us how Brielle climbed the steps of the slide at her day care center by herself, after only being shown once. And I am still captivated by those bright eyes, that infectious smile, and now, her strong ringing laughter and constant chatter, too.

Julie is a shining example of the Power of Parental Persistence. If Julie did not demonstrate a willingness to support Brielle, if she did not have the strength of her convictions to believe that she could help her daughter, none of this would be possible. It is easy to fall into the depths of despair when faced with the incredible, sometimes daunting task of parenting a child with a disability. But just as is the case with the many valiant parents of children with special needs, Julie did not stop for self-pity; she knew that there was work to be done. She knew that information was of great importance and so she learned as much as she could about her daughter's disability. She sought out experts in the field of metabolic disease, and groups like NORD. She learned that she was not alone; that there were other people in the world who cared. She also did not stop after Brielle got the help she needed. Julie went forth and took what she had learned and tried to help others with J.U.M.P. and in her role at Exceptional Parent. She said she wanted to make a difference—and she has!

Julie and her children [illegible]

Congratulations, Julie. Thank you for being a part of the Exceptional Parent Family and for being a constant reminder to all of us of the power of patience, persistence, and love. Good luck and God Speed.

With Great
Admiration
and Respect,

Joseph M Valenzano Jr

Joseph M. Valenzano, Jr.

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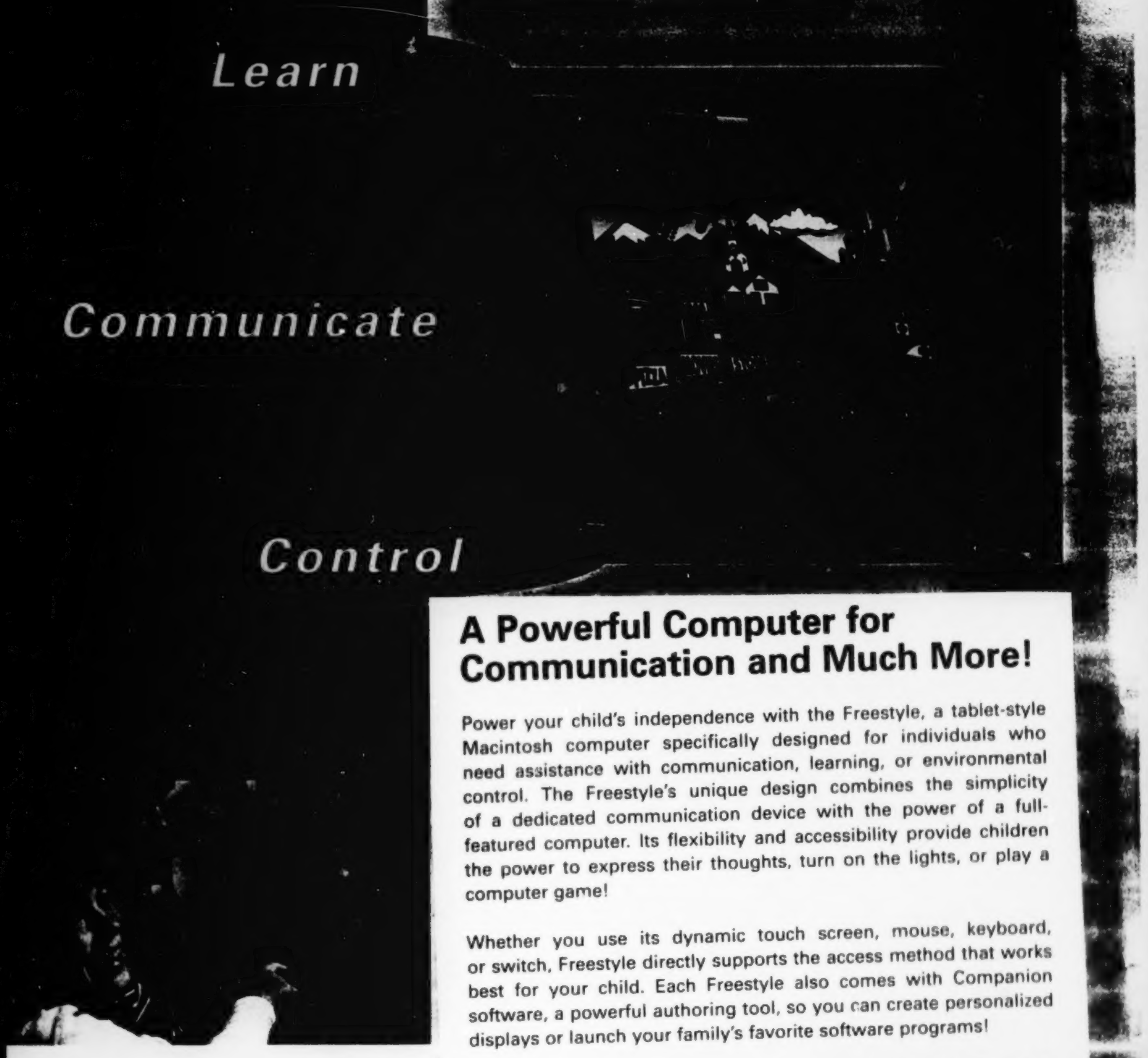

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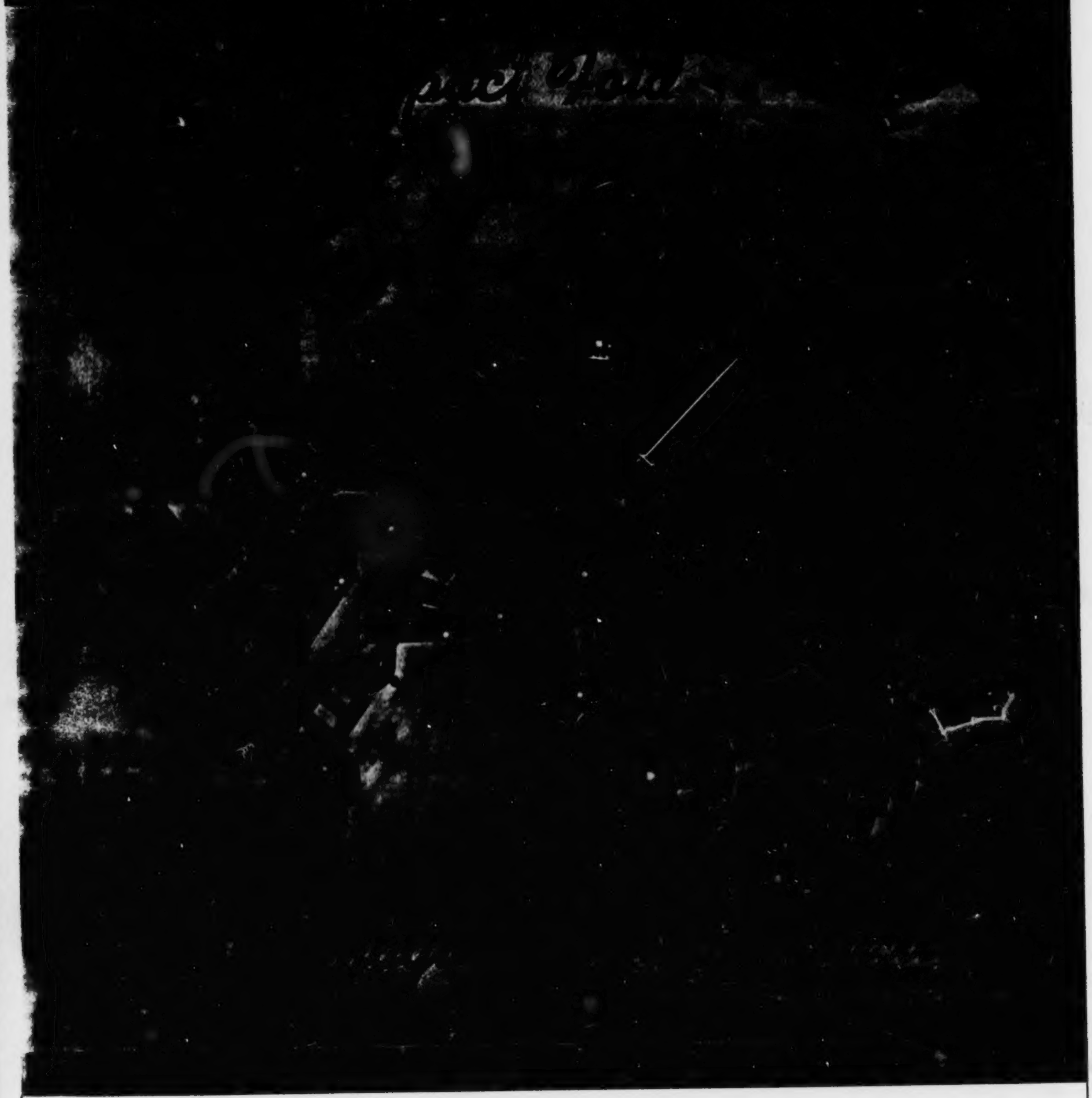

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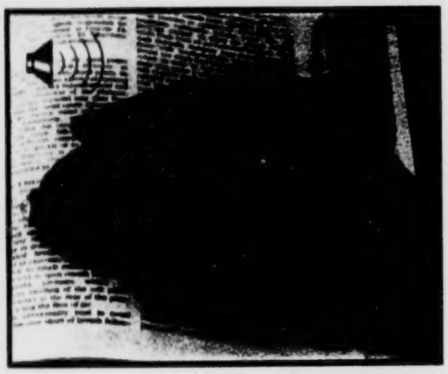

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- *To reach out to mothers and fathers of children and young adults who have disabilities and special healthcare needs.*
- *To empower parents and professionals by providing practical information and emotional support.*
- *To appreciate that parents are the most important experts in the lives of their children.*
- *To energize parents and professionals.*
- *To share ideas and experiences so parents, professionals, people who have disabilities, and other advocates can learn from one another and better collaborate to serve all children and families.*

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RICK RADER, M.D., Director, Institute for Developmental Medicine, Orange Grove Center, Chattanooga TN
HARILYN ROUSSO, A.C.S.W., Director, Disabilities Unlimited Counseling & Consultative Service, New York, NY
HOWARD SHANE, Ph.D., Director, Communications Enhancement Center, Children's Hospital, Boston, MA
HELEN TAGER-FLUSBERG, PH.D, Senior Scientist, Eunice Kennedy Shriver Ctr for Mental Retardation and Developmental Disabilities, Waltham, MA
CAROL TINGEY, Ph.D., Parent, Psychologist, University of Utah Hospital, Salt Lake City, UT
THERESA VARNET, M.S.W., J.D. Partner, private legal firm, Spain, Spain, & Varnet, Chicago, IL

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- Speech
- Occupatinal
- Horicultural
- Multi-Sensory Stimulation
- Pet
- Music

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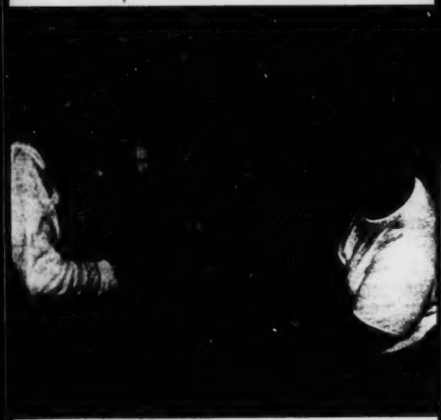

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- Cerebral Palsy
- Brain trauma

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Circle #90

National Resources for Specific Disabilities

This directory includes national groups and organizations that can serve as resources for parents and professionals seeking information and support regarding specific disabilities and conditions. Please note that information on some specific disabilities may also be available from Federal and Federally-Funded Information Resources, Parent to Parent Programs, or certain National Information and Advocacy Resources (see Table of Contents for page numbers). In addition, Matching Resources, at the end of this directory, may also be useful.

CROSS-REFERENCING

Categories have been cross-referenced where appropriate.

Many conditions are known by more than one name. Readers are directed to "See" other relevant category names where resources are also listed. Under CHROMOSOME 4P-, for example, readers are referred to WOLF-HIRSCHHORN SYNDROME.

Some specific disabilities are not covered by a specific national organization. These conditions may be cross-referenced to a broader category that includes organizations that can provide helpful resources. For example, the metabolic condition ARGINASE DEFICIENCY is cross-referenced to UREA CYCLE DISORDERS. In some cases, the reader may be directed to a similar (but not identical) condition, when groups for that condition have indicated the ability and willingness to provide appropriate information and support. For example, 45,X SYNDROME is cross-referenced to TURNER'S SYNDROME and HYPOPIGMENTATION.

In cases where resources are available for both a general category of disability (for example, VISUAL IMPAIRMENT), as well as specific conditions within that general category (for example, ALBINISM; GLAUCOMA; MACULAR DISEASES; RETINITIS PIGMENTOSA; RETINOBLASTOMA; SEPTO-OPTIC DYSPLASIA; and USHER SYNDROME), cross-referencing goes in two directions. Under VISUAL IMPAIRMENTS, for example, readers are informed of the types of visual impairments for which specific resources exist; and under each specific type of visual impairment, readers are referred back to the more general category. The only exception to this type of cross-referencing is the general category MENTAL RETARDATION, which is not used as a cross-referencing term.

In cases where one specific condition usually includes other conditions, but those other conditions do not necessarily include the first condition, cross-referencing goes in one direction only. For example, under LAURENCE-MOON-BARDET-BIEDL SYNDROME (LMBBS), readers are directed to "See also" KIDNEY DISORDERS and RETINITIS PIGMENTOSA, though neither of these conditions refer back to LMBBS. This is because LMBBS typically includes kidney complications and retinitis pigmentosa, but a primary diagnosis of either one of these conditions does not typically include LMBBS.

Cross-referencing assistance came from the organizations listed in this directory, from the National Organization for Rare Disorders (NORD) and their *Resource Guide* (third edition, 1997, available for $43.50 through the Exceptional Parent Library [800] 535-1910; catalogue number NO200D), and from the *Physician's Guide to Rare Diseases* (second edition, 1995, edited by Jess G. Thoene, M.D., which is also available from the Exceptional Parent Library).

USING THIS DIRECTORY

A description of services provided by individual groups follows each listing in this directory. Numbers correspond to items listed in the **Key to Services**, which appears on every other page. When available, e-mail addresses and World Wide Web sites have been included. E-mail addresses are indicated by the symbol, ✉. Web sites are listed with the standard **http://** before each. (Unless otherwise indicated, all telephone numbers are for voice only.)

1-ß-HYDROXYLASE DEFICIENCY
See: Adrenal Disorders

17-20-DESMOLASE DEFICIENCY
See: Adrenal Disorders

17-ALPHA-HYDROXYLASE DEFICIENCYF
See: Adrenal Disorders

17-HYDROXYLASE DEFICIENCY
See: Adrenal Disorders

21-HYDROXYLASE DEFICIENCY
See: Adrenal Disorders

3-ß-HYDROXYSTEROID DEHYDROGENASE DEFICIENCY
See: Adrenal Disorders"

45, X SYNDROME
See: Turner's Syndrome; Hypopigmentation

A-BETA-LIPOPROTEINEMIA
See: Tay-Sachs Disease

ABDOMINAL MIGRAINE
See: Cyclic Vomiting Syndrome

ACHONDROPLASIA
See: Growth Disorders

ACID MALTASE DEFICIENCY
See also: Glycogen Storage Diseases; Muscular Dystrophy

(AMDA) Acid Maltase Deficiency Association
PO Box 700248
San Antonio, TX 78270-0248
(210)494-6144
(210)490-7161 FAX
✉tianrama@aol.com
http://www.members.aol.com/amdapage/index.htm

ACIDEMIA, ISOVALERIC (IVA)
See: Acidemia, Organic

ACIDEMIA, METHYLMALONIC
See: Acidemia, Organic

ACIDEMIA, ORGANIC
See also: Fatty Oxidation Disorder; Maple Syrup Urine Disease; Metabolic Disorders

Organic Acidemia Association
14600 41st Ave. N.
Plymouth, MN 55446
(612) 559-1797
(612) 694-0017 (fax)
✉oaanews@aol.com
http://www.oaanews.org
1,3,6,8,9

ACIDEMIA, PROPIONIC
See: Acidemia, Organic

ACOUSTIC NEUROMA
See also: Balance Disorders & Dizziness; Brain Tumors; Hearing Impairments; Neurofibromatosis; Neurofibromatosis, Type 2; Vestibular Disorders

Acoustic Neuroma Association
PO Box 12402
Atlanta, GA 30355
(404) 237-8023
(404) 237-2704 (fax)
✉anausa@aol.com
http://www.anausa.org
1,2,4,6,8

Acoustic Neuroma Association of Canada
PO Box 369
Edmonton, AB CAN T5J 2J6
(800) 561-2622 (V/TTY, Canada)
(780) 428-3384 (V/TTY)
✉anac@compusmart.ab.ca
http://www.anac.ca
1,2,3,4,5,6,7 French materials

ACQUIRED IMMUNE DEFICIENCY SYNDROME
See: AIDS

ACROCEPHALOSYNDACTYLY, TYPE I
See: Apert Syndrome

ACROFACIAL DYSOSTOSIS, NAGER TYPE
See: Nager & Miller Syndromes

ACROMEGALY
See: Multiple Endocrine Neoplasia I; Pituitary Tumors

ACTH DEFICIENCY
See: Adrenal Disorders

ACYL-COA DEHYDROGENASE DEFICIENCY, MEDIUM-CHAIN
See: Fatty Oxidation Disorder

ADDISON DISEASE
See: Adrenal Disorders

ADIPOGENITAL-RETINITIS PIGMENTOSA-POLYDACTYLY SYNDROME
See: Laurence-Moon-Bardet-Biedl Syndrome

ADRENAL CORTEX MALE PSEUDOHERMAPHRODITISM
See: Adrenal Disorders

ADRENAL DISORDERS

National Adrenal Diseases Foundation
505 Northern Blvd.
Great Neck, NY 11021
(516) 487-4992
✉nadf@aol.com
http://medhlp.netusa.net/www/nadf.htm
1,2,3,4,5

ADRENOCORTICOTROPIC HORMONE DEFICIENCY
See: Adrenal Disorders; Pituitary Tumors

ADRENOGENITAL SYNDROME
See: Adrenal Disorders

ADRENOLEUKODYSTROPHY
See: Leukodystrophy; Tay-Sachs Disease

ADRENOLEUKODYSTROPHY, NEONATAL
See: Leukodystrophy; Tay-Sachs Disease

AGENESIS OF COMMISSURA MAGNA CEREBRI
See: Agenesis of the Corpus Callosum

AGENESIS OF THE CORPUS CALLOSUM
See also: Aicardi Syndrome

ACC Network
5749 Merrill Hall, Rm 18
University of Maine
Orono, ME 04469-5749
(207) 581-3119
(207) 581-3120 (fax)
✉um-acc@maine.maine.edu
3

AGYRIA
See: Lissencephaly

AICARDI SYNDROME
See also: Agenesis of the Corpus Callosum; Epilepsy; Visual Impairments

Aicardi Syndrome Awareness and Support Group
29 Delavan Ave.
Toronto. ON CAN M5P 1T2
(416) 481-4095
2,3,4,7,9

Aicardi Syndrome Newsletter
PO Box 398
Fletcher, OH 45326
(937) 368-2137 (voice/fax)
✉AICNews@aol.com
http://www.Aicardi.com
1,2,3,6,7,8,9

AIDS

CDC National AIDS Hotline
American Society Health Assn.
PO Box 13827
Research Triangle Park, NC 27709
(800) 342-2437
(800) 344-7432 (Spanish)
(800) 243-7889 (TTY)
(919) 361-4855 (fax)
✉hivnet@ashastd.org
http://www.ashastd.org
2,5; Spanish materials

National Pediatric & Family HIV Resource Center
30 Bergen St -ADMC- 4
Newark, NJ 07107
(800) 362-0071
(973) 972-0410
(973) 972-0399 (fax)
✉ortegaes@umdnj.edu
http://www.wdcnet.com/pedsaids
1,2,4,7; Spanish/Creole materials

ALAGILLE SYNDROME
See also: Heart Disorders; Liver Disorders

Alagille Syndrome Alliance
10630 SW Garden Park Pl
Tigard, OR 97223
(503) 639-6217
✉hahn@worlnet.att.net
http://www.athenet.net/~luxhoj/main.html
1,2,3,4,9

ALANINURIA
See: Lactic Acidosis; Acidemia, Organic

ALBINISM & HYPOPIGMENTATION
See also: Visual Impairments

NOAH (National Organization for Albinism and Hypopigmentation)
1530 Locust St, # 29
Philadelphia, PA 19102
(800) 473-2310
(609) 858-4337
✉noah@albinism.org
http://www.albinism.org/
1,2,3,4,5,6,8,9; Spanish materials

ALBRIGHT SYNDROME
See: Growth Disorders

ALGONEURODYSTROPHY
See: Reflex Sympathetic Dystrophy Syndrome

ALLERGY
See: Asthma & Allergy; Food Allergy; Latex Allergy

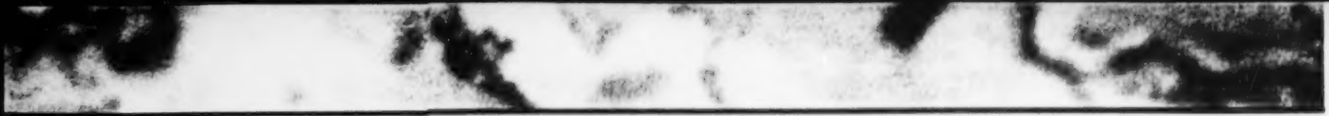
ALLERGY, FOOD
See: Food Allergy

ALLERGY, LATEX
See: Latex Allergy

ALOPECIA AREATANATIONAL

National Alopecia Areata Foundation
710 C St., Ste. 11
San Rafael., CA 94901
(415) 456-4644
(415) 456-4274 (fax)
✉74301.1642@compuserve.com
1,2,3,4,5,6,7,8,9; Spanish materials

ALOPECIA UNIVERSALA-ONYCHODYSTROPHY-TOTAL VITILIGO
See: Ectodermal Dysplasias; Vitiligo



ALOPECIA-ANOSMIA-DEAFNESS-HYPOGONADISM
See: Ectodermal Dysplasias

ALOPECIA-ONYCHODYSPLASIA-HYPOHIDROSIS
See: Ectodermal Dysplasias

ALPHA-1-ANTITRYPSIN (AAT) DEFICIENCY
See also: Liver Disorders; Lung Diseases

Alpha-1 National Association
8120 Penn Ave. South, Ste. 549
Minneapolis, MN 55431
(612) 703-9979
(612) 703-9977 (fax)
✉brandley@alpha1.org
http://www.alpha1.org
1,2,3,4,5,6,7,9

ALPHA-GALACTOSIDASE DEFICIENCY
See: Fabry Disease

ALPORT SYNDROME
See: Hearing Impairments; Kidney Diseases, Hereditary; Vision Impairments

ALSTROM SYNDROME
See also: Diabetes Mellitus; Hearing Impairments; Kidney Disorders; Retinitis Pigmentosa; Visual Impairments

Society for Alstrom Syndrome Families
1006 Howard Rd
Warminster, PA 18974
(215) 674-1936
✉sasf@voicenet.com
http://www.jax.org/alstrom
1,3,9

ALTERNATING HEMIPLEGIA
See: Hemiplegia, Alternating

AMELOCEREBROHYPHOHIDROTIC SYNDROME
See: Ectodermal Dysplasias

AMELOONYCHOHYPHOHIDROTIC DYSPLASIA
See: Ectodermal Dysplasias

AMNIOTIC BANDS
See: Craniofacial Disorders

AMPUTATION
See also: Limb Disorders

American Amputee Foundation
PO Box 250218
Little Rock, AR 72225
(501) 666-2523
(501) 666-8367 (fax)
1,2,4,5,9

Amputee Coalition of America
900 E. Hill Ave., Ste 285
Knoxville, TN
37915-2568
(888) AMP-KNOW (267-5669)
(423) 524-8772
(423) 525-7917
✉ACAOne@aol.com
http://www.amputee-coalition.org.
1,2,3,4,5,6,9,Spanish materials

National Amputation Foundation
38-40 Church St.
Malvern, NY 11565
(516) 887-3600
(516) 887-3667 (fax)
1,2,3,4,7,9

AMSTERDAM DWARF SYNDROME OF DE LANGE
See: Cornelia de Lange Syndrome

AMYLO-1, 6-GLUCOSIDASE DEFICIENCY
See: Glycogen Storage Diseases; Muscular Dystrophy

AMYLOPECTINOSIS
See: Glycogen Storage Diseases

AMYOPLASIA, CONGENITA
See: Arthrogryposis Multiplex Congenita

ANAL ATRESIA
See: Anorectal Malformations

ANAL STENOSIS
See: Anorectal Malformations

ANATHALMIA

International Children's Anathalmia Network
Genetics: Albert Einstein Medical Center
5501 Old York Rd.
Philidelphia, PA 19141
(215) 456-8722
(215) 456-2356 (fax)
http://www.ioi.com/ican

ANDERSEN DISEASE
See: Glycogen Storage Diseases

ANDERSON-FABRY DISEASE
See: Fabry Disease

ANDERSON-WARBURG SYNDROME
See: Norrie Disease

ANEMIA, APLASTIC
See: Anemia, Fanconi; Bone Marrow Transplant

Aplastic Anemia Association of Canada
22 Aikenhead Rd
Etobicoke, ON CAN M9R 2Z3
(416) 235-0468
(519) 235-1756(fax)
http://www.aplastic.ualberta.ca
1,2,4,7,8,9

Aplastic Anemia Foundation of America
PO Box 613
Annapolis, MD 21404-0613
(800) 747-2820
(410) 867-0240
✉aafacenter@aol.com
http://www.aplastic.org
1,2,3,4,5,6,8,9; French/German/ Japanese/Spanish materials

ANEMIA, AREGENERATIVE
See: Anemia, Aplastic

ANEMIA, COOLEY
See: Cooley Anemia

ANEMIA, DIAMOND BLACKFAN
See also: Anemia Aplastic, Anemia Fanconi, Autoimmune Disorders

Diamond Blackfan Anemia Foundation, Inc.
20 Tracy Lynn Ln.
West Seneca, NY 14224
(716) 674-2818
✉dbafoundation@juno.com
1,2,3,4,6,7,8,9

ANEMIA, ERYTHROBLASTOTIC
See: Cooley Anemia

ANEMIA, FANCONI
See also: Anemia, Aplastic; Heart Disorders; Kidney Disorders; Leukemia

Fanconi Anemia Research Fund/Support Group
1902 Jefferson, #2
Eugene, OR 97405
(541) 687-4658
(541) 687-0548 (fax)
(800) 828-4891
✉fafund@rio.com
1,2,6,8; Spanish/Portugese/French materials

ANEMIA, HEMOLYTIC
See: Cooley Anemia

ANEMIA, HYPOPLASTIC
See: Anemia, Aplastic

ANEMIA, MEDITERRANEAN
See: Cooley Anemia

ANEMIA, REFRACTORY
See: Anemia, Aplastic

ANEMIA, TARGET CELL
See: Cooley Anemia

ANEMIA, TOXIC PARALYTIC
See: Anemia, Aplastic

ANGELMAN SYNDROME
See also: Epilepsy

Angelman Syndrome Foundation
414 Plaza Dr., Ste. 209
Westmont, IL 60559-5507
(800) 432-6435
(630) 655-0391
✉asf@adminsys.com
http://www.-chem.ucsd.edu/asf
1,2,3,4,5,6,7,8,9; Internet mail list-subscribe by sending e-mail to: listserv@ucsd.edu

Canadian Angelman Syndrome Society
PO Box 37
Priddis, AB CAN, T0L 1W0
(403) 931-2415 (voice/fax)
✉caff@cadvision.com
1,2,3,5,6,9; French materials

ANGIO-OSTEOHYPERTROPHY SYNDROME
See: Klippel-Trenaunay Syndrome

ANGIOKERATOMA CORPORIS DIFFUSUM
See: Fabry Disease

ANGIOMA
See: Vascular Malformations

ANGIOMATOSIS RETINA
See: Von Hippel-Lindau Syndrome

ANIRIDIA
See: Visual Impairments

ANKYLOSING SPONDYLITIS, JUVENILE
See: Arthritis

ANOPHTHALMIA
See also: Visual Impairments

International Children's Anophthalmia Network
5501 Old York Rd.
Philadelphia, PA 19141
(800) 580-4226
(215) 456-2350 (fax)
1,2,3,4,6,9

ANORECTAL MALFORMATIONS
See also: Intestinal Pseudo-Obstruction Syndrome

Pull-Thru Network
4 Woody Ln.
Westport, CT 06880
(203) 221-7350
(203) 221-9212 (fax)
✉pullthrunw@aol.com
http://www.pullthrough.org
1,2,3,4,9

APECED SYNDROME
See: Ectodermal Dysplasia; Hypoparathyroidism

APERT SYNDROME
See also: Craniofacial Disorders

Apert Support and Information Network
PO Box 1184
Fair Oaks, CA 5528
(916) 961-1092 (voice/fax)
✉apertnet@ix.netcom.com
1,2,3

Apert Syndrome Pen Pal Network
PO Box 115
Providence, RI 02901
(401) 421-9076
3,5,9

Apert Syndrome Support Group
8708 Kathy St
St. Louis, MO 63126
(314) 965-3356
3,4,5

APHASIA, ACQUIRED
See also: Brain Injury; Stroke

National Aphasia Association
156 Fifth Ave, Ste. 707
New York, NY 0010
(800) 922-4622
(212) 989-7777 (fax)
✉klein@aphasia.org
http://www.aphasia.org
1,2,3,4,5

APLASTIC ANEMIA
See: Anemia, Aplastic

APNEA, INFANTILE
See: Apnea, Sleep

APNEA, SLEEP

American Sleep Apnea Association
1424 K Street NW Ste. 302
Washington, DC 20005
(202) 293-3656
✉asaa@sleepapnea.org
http://sleepapnea.org
1,2,,5,6,8

APRAXIA
See also: Learning Disabilities

National Organization for Apraxia and Dyspraxia
7675 Charter Oaks Dr.
Pensacola, FL 32514
(904) 478-4895 (voice/fax)
(904) 494-1444 (TTY)
✉dyspraxia@aol.com
1,2,3,4,7,9

AQUEDUCTAL STENOSIS
See: Hydrocephalus

ARACHNODACTYLY
See: Marfan Syndrome

AREGENERATIVE ANEMIA
See: Anemia, Aplastic

ARGINASE DEFICIENCY
See: Urea Cycle Disorders

ARGININOSUCCINASE DEFICIENCY
See: Urea Cycle Disorders

ARGININOSUCCINIC ACID SYNTHETASE DEFICIENCY
See: Urea Cycle Disorders

ARGININOSUCCINIC ACIDURIA
See: Urea Cycle Disorders

ARNOLD-CHIARI MALFORMATION
See also: Spina Bifida; Syringomyelia

Arnold-Chiari Family Network
c/o Maureen & Kevin Walsh
67 Spring St
Weymouth. MA 02188
(617) 337-2368
2,3

ARTERIOHEPATIC DYSPLASIA
See: Alagille Syndrome

ARTERIOVENOUS MALFORMATIONS (AVMS)
See also: Epilepsy; Stroke; Vascular Malformations

AVM Support Group of Nevada
PO Box 1261
Fernley, NV 89408
(702) 575-5421
2,3,4

ARTHRO-OPTHALMOPATHY
See: Stickler Syndrome

ARTHRITIS

American Juvenile Arthritis Organization
1330 W. Peachtree St.
Atlanta, GA 30309
(800) 283-7800
(404) 872-7100
(404) 872-9559 (fax)
http://www.arthritis.org
✉jaustin@arthritis.org
1,2,4,7,8; Spanish materials

Arthritis Society
#1700, 393 University Ave.
Toronto, ON CAN M5G 1E6
(800) 321-1433(CAN only)
(416) 979-7228
(416) 979-8366 (fax)
✉nkent@arthritis.ca
http://www.arthritis.ca
1,2,6,8; French materials

ARTHROCHALASIS MULTIPLEX CONGENITA
See: Ehlers-Danlos Syndrome

ARTHROGRYPOSIS MULTIPLEX CONGENITA
See also: Growth Disorders;

KEY TO SERVICES

1 Periodical/newsletter
2 Informational materials
3 Networking/matching
4 Referrals to local resources
5 Local chapters
6 National conferences
7 National advocacy efforts
8 Fund research
9 Maintain research registry

National Resources for Specific Disabilities

Muscular Dystrophy

AVENUES: A National Support Group for Arthrogryposis Multiplex Congenita
PO Box 5192
Sonora, CA 95370
(209) 928-3688
✉avenues@sonnet.com
http://www.sonnet.com/avenues
1,2,3,4

CAST: Canadian Arthrogryposis Support Team
365 Fiddler's Green Rd S
Ancaster, ON CAN L9G 1X2
(905) 648-2007
✉cast@freenet.hamilton.on.ca
1,2,3,4,5

ASCENDING PARAYLSIS

See: Guillain-Barré Syndrome

ASPERGER SYNDROME

See: Autism

ASTHMA

See: Asthma & Allergy

ASTHMA & ALLERGY

See also: Food Allergy; Latex Allergy; Lung Diseases

Allergy and Asthma Network Mothers of Asthmatics, Inc.
2751 Prosperity Ave., Ste.150
Fairfax, VA 22031-4397
(703) 641-9595
(703) 573-7794 (fax)
(800) 878-4403
✉aanma@aol.com
http://www.aanma.org
1,2,4,5,6

Allergy/Asthma Information Association
30 Eglinton Ave W, Ste. 750
Mississauga, ON. CAN L5R 3E7
(905) 712-2242
(905) 712-2245 (fax)
1,2,4,5,6,7,9; French materials

Asthma and Allergy Foundation of America
1233 20th Street, N.W. Ste. 402
Washington, DC 20036
(800) 727-8462
(202) 466-7643
(202) 466-8940 (fax)
✉info@aafa.org
http://www.aafa.org
1,2,3,4,5,6,7,8; Spanish materials

Asthma Society of Canada
130 Bridgeland Ave., Ste. 425
Toronto, ON CAN M6A 1Z4
(416) 787-4050
(416) 787-5807 (fax)
1,2,3,4,8

ATAXIA

See also: Ataxia Telangiectasia; Charcot-Marie-Tooth Disease; Friedreich Ataxia; Von Hippel-Lindau Syndrome

National Ataxia Foundation
2600 Fernbrook Lane, Ste. 119
Minneapolis, MN 55447-4752
(612)553-0020
(612)553-0167 (fax)
✉naf@mr.net
http://www.ataxia.org
1,2,3,4,5,6,7,8;

ATAXIA, FAMILIAL

See: Ataxia; Friedreich Ataxia

ATAXIA, FRIEDREICH

See: Ataxia; Friedreich Ataxia

ATAXIA, SPINOCEREBELLAR

See: Ataxia; Friedreich Ataxia

ATAXIA, TELANGIECTASIA

See also: Ataxia; Autoimmune Disorders; Cancer; Immune Disorders; Leukemia

Ataxia Telangiectasia Children's Project
1W Camino Real, # 212
Boca Raton, FL 33432-5966
(800) 543-5728
(561) 395-2621
(561) 395-2640 (fax)
✉betsy@atcp.org
✉rosa@atcp.org
✉bradmargus@atcp.org
http://www.atcp.org
1,2,3,4,6,7,9; Spanish materials

ATAXIA WITH LACTIC ACIDOSIS II

See: Ataxia; Leigh Disease

ATRESIA

See: Microtia

ATRIAL SEPTAL DEFECTS

See: Heart Disorders

ATROPHIA BULBORUM HEREDITARIA

See: Norrie Disease

ATTENTION DEFICIT DISORDER

The ADHD Challenge
PO Box 488
West Peabody, MA 01985-7277
(800) 233-2322
(978) 535-3276 (info)
✉koplow@grs.net
1,2,4; prescription drug discount program

Learning Disabilities

AD-IN: Attention Deficit Information Network
475 Hillside Ave.
Needham, MA 02494
(781) 455-9895
(781) 444-5466 (fax)
✉adin@gis.net
http://www/.addinfonetwork.com
2,3,4,5,6,8

CHADD-Canada, Inc.-Children and Adults with Attention Deficit Disorder
1376 Bank Street, Ste. 214
Ottawa ON, Canada K1H 1B3
(301) 306-7070
(301) 306-7090 (fax)
✉chaddcanad@hotmail.com
http://www.chadd.org
http://www.members.tripod.com/~chaddcanada/index.html
1,2,3,5,6,9; Spanish materials

CHADD: Children and Adults with Attention Deficit Disorders
8181 Professional Place, Suite 201
Landover, MD 20785
(800) 233-4050
(301) 306-7070
(301) 306-7090
✉national@Chadd.org
http://www.Chadd.org
1,2,3,5,6,9; Spanish materials

National ADD Association
PO Box 972
Mentor, OH 44061
(800) 487-2282
(440) 350-9595
(440) 350-0223
http://www.add.org
✉mail@add.org
1,2,4,6

AURICULO-OCULO-VERTEBRAL SYNDROME

See: Goldenhar Syndrome

AUTISM

See also: Autism and Sensory Impairments; Language Disorders

Autism Research Institute
4182 Adams Ave.
San Diego, CA 92116
(619) 281-7165
(619) 563-6840 (fax)
http://www.autism.com/autism
1,2,4,5,9

Autism Society of America
7910 Woodmont Ave. Ste. 650
Bethesda, MD
(800) 328-8476
(301) 657-0881
(301) 657-0869 (fax)
http://www.autism-society.org/
1,2,4,5,6,7,8; Chinese/French/Spanish/Vietnamese materials

Autism Society of Canada
129 Yorkville Ave, #202
Toronto, ON CAN M5R 1C4
(416) 922-0302 (voice/fax)
(416) 922-1032 (fax)
1,2,4,7; French materials

Center for Study of Autism
PO Box 4538
Salem, OR 97302
(503) 363-9110 (voice/fax)
✉sait@teleport.com
http://www.autism.org/
2,6

MAAP Services, Inc.
PO Box 524
Crown Point, IN 46307
(219) 662-1311
(219) 662-0638 (fax)
✉chart@netnitco.net
http://ww2.netnitco.net/users/chart/maap.htm
1,2,5,6

National Autism Hotline/Autism Services Center
605 Ninth St Prichard Bldg.
PO Box 507
Huntington, WV 25710-0507
(304) 525-8014
(304) 525-8026 (fax)
2,3,5,7; Spanish/Italian/French materials

AUTISM AND SENSORY IMPAIRMENTS

See also: Hearing Impairments; Visual Impairments

The Autism Network for Hearing & Visually Impaired Persons
c/o Dolores and Alan Bartel
7510 Oceanfront Ave.
Virginia Beach, VA 23451
(804) 428-9036
(804) 428-0019 (fax)
3,4,7,9

AUTOIMMUNE DISORDERS

See also: Immune Disorders; Vitiligo

American Autoimmune Related Diseases Association
22100 Gratiot Ave.
East Detroit, MI 48021
(810) 776-3900
(800) 598-4668
✉aarda@aol.com
http://www.aarda.org
1,2,4,8

AUTOIMMUNE MYOCARDITIS

See: Autoimmune Disorders

AVM

See: Arteriovenous Malformations (AVMs)

B12 METABOLISM; INBORN ERROR OF

See: Cobalamin (B12) Defiency

BAISCH SYNDROME

See: Ectodermal Dysplasias

BALANCE DISORDERS & DIZZINESS

See also: Vestibular Disorders

EAR Foundation
1817 Patterson St.
Nashville, TN 37203-2110
(800) 545-4327 (V/TTY)
(615) 329-7807
(615) 329-7935 (fax)
✉ear@earfoundation.org
http://www.earfoundation.org
1,2

BANNAYAN, RUVALCABA, RILEY-SMITH SYNDROME

See: Sotos Syndrome

BARDET-BIEDL SYNDROME

See: Laurence-Moon-Bardet-Biedl Syndrome

BATTEN DISEASE

See also: Tay-Sachs Disease

Batten Disease Support and Research Association
2600 Parsons Ave.
Columbus, OH 43207
(800) 448-4570
(740) 927-4298
✉bdsra1@bdsra.com
http://www.bdsra.org
1,2,3,4,5,6,8,9; Spanish/Portugese/German/Frecnh materials

Batten Disease Support and Research Association, Canadian Chapter
c/o Bev Maxim
17 Bell St.
Regina, SK CAN S4S 4B7
[illegible]6) 789-9047
[illegible]bdsra1@bdsra.org
http://www.bdsra.org
1,2,3,4,5,6,7,8,9

Children's Brain Diseases Foundation
350 Parnassus Ave., Ste. 900
San Francisco, CA 94117
(415) 566-5402
(415) 565-6259
(415) 863-3452 (fax)
http://www.children'sneuronet.org
1,2,3,6,7,8

National Batten Disease Registry
1050 Forest Hill Rd.
Staten Island, NY 10314-6399
(800) 952-9628
(718) 494-5201
(718) 982-6346 (fax)
✉dockteeb@nyucomr.em1.com
2,3,4,5,6,8,9; genetic counseling, diagnostic testing

BATTEN-MAYOU SYNDROME

See: Batten Disease

BATTEN-SPIELMEYER-VOGT DISEASE

See: Batten Disease

BBB SYNDROME

See: Opitz Syndrome

BBBG SYNDROME

See: Opitz Syndrome

BECKER MUSCULAR DYSTROPHY

See: Muscular Dystrophy

BECKWITH-WIEDEMANN SYNDROME

Beckwith-Wiedemann Support Network
2711 Colony Rd
Ann Arbor, MI 48104
(800) 837-2976 (Parents only)
(734) 973-0263
(734) 973-9721 (fax)
✉A800BWSN@aol.com
1,2,3,4,6

BEDWETTING

See: Incontinence

BEHCET'S DISEASE

See: Autoimmune Disorders

BELL'S PALSY

Bell's Palsy Research Foundation
9121 E. Tanque Verde
Ste. 105-286
Tuscon, AZ 85749
(520)749-4614
(520)749-0489
✉BellsPalsy@aol.com
2,3,4,8,9

BENIGN CONGENITAL HYPOTONIA

See also: Spinal Muscular Atrophy

Bereavement Support Center for Loss in Multiple Birth
PO Box 1064
Palmer, AK 99645-1064
(907) 746-6123
✉climb@pobox.alaska.net
1,2,3,4,7

BEREAVEMENT SUPPORT

Center for Loss in Multiple Birth
PO Box 1064
Palmer, AK 99645-1064
(907) 746-6123
✉climb@pobox.alaska.net
http://www.climb-support.org
1,2,3,5,6

The Compassionate Friends, Inc.
(Offering support to families who have experienced the death of a child.)
PO Box 3696
Oak Brook, IL 60522-3696
(630) 990-0010
(630) 990-0246 (fax)
✉tcf_national@prodigy.com
http://www.compassionatefriends.org
1,2,3,4,5,6; Spanish materials

Pen-Parents
PO Box 8738
Reno, NV89507-8738
(702) 826-7332
(702) 826-0632 fax)
✉PenParents@prodigy.com
http://www.pages.prodigy.com/nv/fgck08a/penparents.html
1,2,3,4

Pregnancy and Infant Loss Center
1421 E. Wayzata Blvd., #30
Wayzata, MN 55391
(612) 473-9372
(612) 473-8978 (fax)
1,2,4; Spanish materials

BERGER DISEASE
See: Kidney Disorders

BETA THALASSEMIA MAJOR
See: Cooley Anemia

BEUREN SYNDROME
See: Williams Syndrome

BIOTINIDASE DEFICIENCY
See: Metabolic Disorders

BIRTHMARK
See: Nevi, Giant Congenital; Vascular Malformations

BLEEDING DISORDERS
See: Hemophilia

BLEPHAROPHIMOSIS, PTOSIS, EPICANTHUS INVERSUS SYNDROME (BPES)
See also: Craniofacial Disorders

Blepharophimosis, Ptosis, Epicanthus Inversus Support Group
c/o Lynne Schauble
SE 820 Meadow Vale Dr.
Pullman, WA 99163
(509) 332-6628
✉lschauble@wsu.edu
1,2,3,7,9

BLEPHAROSPASM
See: Dystonia

BLINDNESS
See: Visual Impairments

BLOCH-SULZBERGER SYNDROME
See: Incontinentia Pigmenti

BLOOD VESSEL MALFORMATIONS
See: Vascular Malformations

BLOOM SYNDROME
See also: Cancer; Immune Disorders; Growth Disorders; Short Stature

Bloom Syndrome Registry
Laboratory of Human Genetics
NY Blood Ctr.
310 E. 67th St.
New York, NY 10021
(212) 570-3075
(212) 570-3376
(212) 570-3195 (fax)
✉mproytch@server.nybc.org
8

BONE MARROW TRANSPLANT
See also: Cancer

Blood & Bone Marrow Transplant Information Network
2900 Skokie Valley Rd., Ste B
Highland Park, IL 60035
(888) 597-7674
(847) 433-3313
(847) 433-4599 (fax)
✉help@bmtnews.org
http://www.bmtnews.org
1,2,3,9; legal referral for insurance problems

BONE TUMOR-EPIDERMOID CYST-POLYPOSIS
See: Peutz-Jeghers Syndrome; Polyposis

BONNEVIE-ULRICH SYNDROME
See: Turner Syndrome

BOOK SYNDROME
See: Ectodermal Dysplasias

BOURNEVILLE PRINGLE SYNDROME
See: Tuberous Sclerosis

BOWEL DYSFUNCTION/ IRRITABLE BOWEL SYNDROME
See also: Gastrointestinal Disorders

International Foundation for Functional Gastrointestinal Disorders (IFFGD)
PO Box 17864
Milwaukee, WI 53217
(888)964-2001
(414) 964-1799
(414) 964-7176 (fax)
✉IFFGD@iffgd.org
http://www.iffgd.org
1,2,4,5 (referrals to local physicians),6,9; One-one telephone support.

BRACHIAL PLEXUS INJURY
See: Erb Palsy

BRACHMANN-DE LANGE SYNDROME
See: Cornelia de Lange Syndrome

BRAIN ATTACK
See: Stroke

BRAIN INJURY
See also: Aphasia, Acquired

Brain Injury Association
105 N. Alfred St.
Alexandria, VA 22314
(800) 444-6443 (family helpline)
(703) 236-6000
(703) 236-6001 (fax)
✉familyhelpline@biaus.org
http://www.biausa.org
1,2,3,4,5,6,7,8; Spanish materials

BRAIN STEM MALFORMATIONS
See: Arnold-Chiari Malformation; Joubert Syndrome; Syringomyelia

BRAIN TUMORS
See also: Acoustic Neuroma; Brain Injury; Cancer; Epilepsy; Pituitary Tumors; Von Hippel-Lindau Syndrome

American Brain Tumor Association
2720 River Rd., Ste. 146
Des Plaines, IL 60018
(800) 886-2282
(847) 827-9910
(847) 827-9918 (fax)
✉info@abta.org
http://www.abta.org
1,2,3,4,5,6,7 Spanish materials

Brain Tumor Foundation for Children, INC
1835 Savoy Dr., Ste. 316
Atlanta, GA 30341
(770) 458-5554
(770) 458-5467 (fax)
✉btfc@bellsouth.net
http://www.btfcgainc.org
1,2,3,4,5,6

Brain Tumor Foundation of Canada
650 Waterloo St., Ste. 100
London, ON CAN N6B 2R4
(519) 642-7755
(519) 642-7192 (fax)
✉eallman1@juno.com
http://www.btfc.org
1,2,3,4,6,8,9; French materials

Brain Tumor Society
124 Watertown St., Ste. 3-H
Watertown, MA 02134-1245
(800) 770-8287
(617) 924-9997
(617) 924-9998 (fax)
✉info@tbts.org
http://www.tbts.org
1,2,3,6,7,8

Children's Brain Tumor Foundation
274 Madison Ave Ste. 1301
New York, NY 10016
(212) 448-9494
(212) 448-1022 (fax)
http://www.childrensneuronet.org
1,2,3,4,6,8

National Brain Tumor Foundation
Cathy Clarence
785 Market St., Ste. 1600
San Francisco, CA 94103
(800) 934-2873 (info line)
(415) 284-0208
(415) 284-0209 (fax)
✉nbtf@braintumor.org
http://www.braintumor.org
1,2,3,4,6,8

BRANCHED CHAIN KETONURIA
See: Maple Syrup Urine Disease

BRANCHER DEFICIENCY
See: Glycogen Storage Diseases

BRANCHIO-OTO-RENAL SYNDROME
See: Craniofacial Disorders; Hearing Impairments; Kidney Disorders

BRITTLE BONE DISEASE
See: Osteogenesis Imperfecta

BROAD THUMB-HALLUX SYNDROME
See: Rubinstein-Taybi Syndrome

BURKE SYNDROME
See: Shwachman Syndrome

BURNS

Phoenix Society for Burn Survivors
2153 Wealthy SouthEast, Ste. 215
East Grand Rapids, Michigan 49506
(800) 888-2876
(616) 458-2773
(616) 458-2831 (fax)
✉info@Phoenix-Society.org
http://www.phoenix-society.org
1,2,3,4,5,6,7,9

CALLOSAL AGENESIS
See: Agenesis of the Corpus Callosum; Aicardi Syndrome

CAMARENA SYNDROME
See: Ectodermal Dysplasias

CAMPTOMELIC SYNDROME
See: Growth Disorders; Short Stature

CANAVAN DISEASE
See: Leukodystrophy; Tay-Sachs Disease

CANCER
See also: Bone Marrow Transplant; Brain Tumors; Leukemia; Polyposis

American Cancer Society
1599 Clifton Rd NE
Atlanta, GA 30329-4251
(800) 227-2345
(404) 320-3333
(404) 982-3676
http://www.cancer.org
2,4,5,7,8; Spanish materials

Canadian Cancer Society
10 Alcorn Ave, Ste 200
Toronto, ON CAN M4V 3B1
(416) 961-7223
(416) 961-4189 (fax)
✉ffernand@cancer.ca
http://www.cancer.ca
1,2,3,4,5,7,8; French materials

Candlelighters Childhood Cancer Foundation
7910 Woodmont Ave., Ste. 460
Bethesda, MD 20814
(800) 366-2223
(301) 718-2686 (fax)
✉info@candlelighters.org
http://www.candlelighters.org
1,2,3,4,5,7; Survivers of Childhood Cancer program, speakers bureau

Childhood Cancer Foundation-Candlelighters Canada
55 Eglinton Ave E, Ste. 401
Toronto, ON CAN M4P 1G8
(800) 363-1062 (Canada only)
(416) 489-6440
(416) 489-9812 (fax)
✉staff@candlelighters.ca
http://www.candlelighters.ca
1,2,3,4,5,6,7; French/Dutch/Finnish/Polish/German materials

CANCER; BRAIN
See: Brain Tumors

CANCER; GASTROINTESTINAL
See: Peutz-Jeghers Syndrome; Polyposis

CARBAMYL PHOSPHATE SYNTHETASE (CPS) DEFICIENCY
See: Urea Cycle Disorders

CARDIAC DISORDERS
See: Heart Disorders

CARDIO-FACIO-CUTANEOUS SYNDROME
See also: Heart Disorders; Ichthyosis

CFC Family Network, Inc.
183 Brown Rd.
Vestel, NY 13850
(607) 772-9666
(607) 748-0409 (fax)
✉cliffordIV@juno.com
1,3,9

CAREY SYNDROME
See: Ectodermal Dysplasias

CARNITINE DEFICIENCY SYNDROMES
See also: Acidemia, Organic; Fatty Oxidation Disorder; Mitochondrial Disorders; Muscular Dystrophy

Assistance for Babies and Children with Carnitine Deficiency - ABCD Inc.
1010 Jorie Blvd., Ste. 234
Oak Brook, IL 60521
(800) 554-2223
(630) 571-9608
(630) 472-1744 (fax)
1,2,3,4,7,8,9

CARNITINE PALMITYL TRANSFERASE DEFICIENCY
See: Acidemia, Organic; Fatty Oxidation Disorder; Carnitine Deficiency Syndromes; Muscular Dystrophy

CARPENTER SYNDROME
See also: Craniofacial Disorders

Carpenter Syndrome Network
c/o Cathy Sponsler
P.O. Box 4215-48
20516 High Line Rd.
Tehachapi, CA 93561
(805) 823-0963
✉carpenter.syndrome@php.com
1,3,4,6

CARTILAGE-HAIR HYPOPLASIA
See: Dwarfism; Growth Disorders; Short Stature

CARTILAGNOUS ENCHONDROSES, MULTIPLE
See: Ollier Disease

CAT'S CRY SYNDROME
See: Cri Du Chat Syndrome

CAUSALGIA SYNDROME
See: Reflex Sympathetic Dystrophy Syndrome

CELIAC DISEASE
See also: Celiac Sprue; Gluten Intolerance

Canadian Celiac Association
190 Britannia Rd E Unit 11
Mississauga, ON CAN L4Z 1W6
(905) 507-6208
(905) 507-4673 (fax)
http://www.celiac.ca
1,2,4,5,6,7,8,9; French materials

Celiac Disease Foundation
13251 Ventura Blvd., #1
Studio City
Los Angeles, CA 91604-1838
(818) 990-2354
(818) 990-2379 (fax)
✉cdf@celiac.org
http://www.celiac.org
1,2,3,9

CELIAC SPRUE
See also: Celiac Disease; Gluten Intolerance

American Cedliac Society
IA 58 Musano Ct.
West Orange, NJ 07052
(973) 325-8837
(973) 669-8808 (fax)
1,2,4,5,6; speakers bureau

American Celiac Society Dietary Support Coalition
59 Cuptal Ave.
West Orange, NJ 07052
(973) 325-8837
(973) 669-8808 (fax)
✉bentleac@umdnj.edu
1,2,3,4,5,6,7,8; Speakers bureau.

KEY TO SERVICES

1 Periodical/newsletter
2 Informational materials
3 Networking/matching
4 Referrals to local resources
5 Local chapters
6 National conferences
7 National advocacy efforts
8 Fund research
9 Maintain research registry

National Resources for Specific Disabilities

Celiac Sprue Association
PO Box 31700
Omaha, NE 68131-0700
(402) 558-0600
(402) 558-1347 (fax)
✉celiacs@csaceliacs.org
http://www.csacoliacs.org
1,2,3,4,5,6,8

CENTRAL HYPOVENTILATION SYNDROME, CONGENITAL
See also: Apnea, Sleep; Intestinal Pseudo-Obstruction Syndrome; Ventilator Use

Congenital Central Hypoventilation Syndrome Parent Network
71 Maple St.
Oneonta, NY 13820
✉vanderlaanm@hartwick.edu
1,2,3,6,7,9

CEREBELLAR HYPOPLASIA
See: Joubert Syndrome

CEREBELLAR VERMIS APLASIA/HYPOPLASIA
See: Joubert Syndrome

CEREBELLO-OCULOCUTANEOUS TELANGIECTASIA
See: Ataxia Telangiectasia

CEREBELLORETINAL HEMANGIOBLASTOMATOSIS
See: Von Hippel-Lindau Syndrome

CEREBRAL GIGANTISM
See: Sotos Syndrome

CEREBRAL PALSY

Ontario Federation for Cerebral Palsy
1630 Lawrence Ave. W, Ste. 104
Toronto, ON CAN M6L 1C5
(416) 244-9686
(416) 244-6543 (fax)
✉ofcp@ofcp.on.ca
http://www.ofcp.on.ca
1,2,3,4,5,6,9; French materials

United Cerebral Palsy Associations
1660 L St. NW, Ste. 700
Washington, DC 20036-5602
(800) 872-5827
(202) 776-0406
(202) 776-0414 (fax)
(202) 973-7197 (TTY)
✉ucpainc@aol.com
http://www.ucpa.org
1,2,3,4,5,6,7,8; Spanish materials, provides direct services through 158 affiliate programs

CEREBROOCULORENAL DYSTROPHY
See: Lowe Syndrome

CEREBROSIDE LIPIDOSIS
See: Gaucher Disease

CEREBROTENDINOUS
See: Xanthomatosis Leukodystrophy; Tay-Sachs Disease

CHAGAS' DISEASE
See: Autoimmune Disorders

CHALASODERMIA
See: Connective Tissue Disorders

CHANARIN-DORFMAN SYNDROME
See: Ichthyosis

CHANDS ASSOCIATION
See: Ectodermal Dysplasias

CHARCOT-MARIE-TOOTH DISEASE
See also: Ataxia; Muscular Dystrophy; Myelin Disorders

Charcot-Marie-Tooth Association
601 Upland Ave.
Upland., PA 19015
(800) 606-2682
(610) 499-7486
(610) 499-7487 (fax)
✉cmtassoc@aol.com
http://www.charcot-marie-tooth.org
1,2,4,5,7,6,8,9; Spanish materials

Charcot-Marie-Tooth International
1 Springbank Dr.
St Catharines, ON CAN L2S 2K1
(905) 687-3630
(905) 687-8753 (fax)
✉cmtint@vaxxine.com
http://www.cmtint.org
1,2,3,5,7,9; Scholarship program for members.

CHARGE ASSOCIATION
See also: Heart Disorders; Hearing Impairments Velo-Cardio-Facial Syndrome; VATERL Association; Visual Impairments

CHARGE Syndrome Foundation
2004 Parkade Blvd.
Columbia, MO 65202-3121
(800) 442-7604
(573) 499-4694 (voice/fax)
✉marion@chargesyndrome.org
http://www.chargesyndrome.org
1,2,3,4,6,8

CHEDIAK HIGASHI SYNDROME
See: Hermansky-Pudlak Syndrome

CHEMKE SYNDROME
See: Hydrocephalus; Lissencephaly

CHIARI MALFORMATION
See: Arnold-Chiari Malformation

CHILD SYNDROME
See: Ichthyosis

CHOLESTATIS WITH PERIPHERAL PULMONARY STENOSIS
See: Alagille Syndrome

CHOLESTERYL ESTER STORAGE DISEASE
See: Tay-Sachs Disease

CHONDRODYSPLASIA PUNCTATA
See: Growth Disorders; Ichthyosis

CHORIONIC VILLUS SAMPLING, RELATED DISABILITIES
See also: Limb Disorders

CVS Parent Network Support Group
15706 Reynolds Ln.
Oak Forest, IL 60452
(708) 535-2864
✉midsun@aol.com
1,2,3,4,7,9

CHOROIDEREMIA
See: Macular Diseases; Retinitis Pigmentosa; Visual Impairments

CHRIST-SIEMENS-TOURAINE SYNDROME
See: Craniofacial Disorders; Ectodermal Dysplasias

CHROMOSOME 13 & 18 DISORDERS
See also: Chromosome 18 Disorders

SOFT Canada: Support Organization for Trisomy 18, 13 and Related Disorders
760 Brant St, Ste. 420
Burlington, ON CAN L7R 4B8
(800) 668-0898 (Canada only)
(905) 632-7755
(905) 632-5997 (fax)
✉barbsoft@aol.com
http://www.trisomy.org
1,2,3,4,5,6,8,9; also covers other rare trisomy disorders

SOFT: Support Organization for Trisomy 18, 13 and Related Disorders
2982 S Union St.
Rochester, NY14624
(800) 716-7638
(716) 594-4621 (voice/fax)
✉barbsoft@aol.com
http://www.trisomy.org
1,2,3,5,6,9; also covers other rare trisomy disorders

CHROMOSOME 4P-
See: Wolf-Hirschorn Syndrome

CHROMOSOME 17P-
See: Smith-Magenis Syndrome

CHROMOSOME 18 DISORDERS
See also: Chromosome 13 & 18 Disorders

Chromosome 18 Registry & Research Society
6302 Fox Head
San Antonio, TX 78247
(210) 657-4968 (voice/fax)
✉CODY@UTHSCSA.EDU
chr18.uthscsa.edu
1,3,4,6,8,9

CHROMOSOME 21 RING
See: Chromosome Deletions

CHROMOSOME 22 RING
See also: Chromosome Deletions

Chromosome 22 Central
232 Kent Ave.
Timmins, Ontario CAN P4N 3C3
(705)268-3099 (v/fax)
✉mum2_1@hotmail.com
http://www.nt.net/~a815/chr22.htm
1,2,3,9: Covers all Chromosome 22-related disorders.

CHROMOSOME 3, MONOSOMY 3P2
See: Chromosome Deletions

CHROMOSOME 4 RING
See; Chromosome Deletions; Wolf-Hirschhorn Syndrome

CHROMOSOME 45,X
See: Turner Syndrome

CHROMOSOME 45,X/46,XX
See: Turner Syndrome

CHROMOSOME 46XY/47,XXY
See: Klinefelter Syndrome

CHROMOSOME 47,XXY
See: Klinefelter Syndrome

CHROMOSOME 47,XYY
See: Klinefelter Syndrome

CHROMOSOME 48,XXXY
See: Klinefelter Syndrome

CHROMOSOME 48,XXYY
See: Klinefelter Syndrome

CHROMOSOME 49,XXXXY
See: Klinefelter Syndrome

CHROMOSOME 4P-
See: Wolf-Hirshhorn Syndrome

CHROMOSOME 5P-
See: Cri Du Chat Syndrome

CHROMOSOME 8P DISORDERS

8p Duplication Support Group
Genetics Ctr.
Children's Medical Ctr.
1 Children's Plaza
Dayton, OH 45404
(937) 226-8408
(937) 463-5325 (fax)
✉genemail@aol.com
3,4,9

CHROMOSOME 9 DISORDERS

Support Group for Monosomy 9p
43304 Kipton Nickle Plate Rd.
La Grange, OH 44050
(440) 775-4255
3

Trisomy 9 International Parent Support
Children's Hospital of Michigan
3901 Beaubien Blvd.
Detroit, MI 48201-2196
(313) 745-4513
(313) 745-4827 (fax)
2,3

CHROMOSOME 9 RING
See: Chromosome Deletions; Craniofacial Disorders

CHROMOSOME DELETIONS

Chromosome Deletion Outreach
Box 724
Boca Raton, FL 33429-0724
(800) CDO-6880 (toll-free family helpline)
(561) 391-5098
(561) 395-4252 (fax)
✉cdo@worldnet.att.net
http://www.members.aol.com/cdousa/cdo.htm
1,2,3,9; Also deals with chromosome translocations

CHROMOSOME DISORDERS
See also: Chromosome 13 & 18 Disorders

Chromosome 22 Central
232 Kent Ave.
Timmin, ON CAN P4N 3C3
(705) 268-3099 (voice/fax)
✉mum2_1@hotmail.com
http://www.nt.net/~a815/chr22.htm
1,2,3,9

CHROMOSOME INVERSIONS

National Center on Chromosome Inversions
1029 Johnson St.
Des Moines, IA 50315
(515) 287-6798 (voice/fax)
✉Jackie/Barker@hotmail.com
3,9

CHROMOSOME TRANSLOCATIONS
See: Chromosome Deletions

CHROMOSOME TRISOMY DISORDERS
See: Chromosome 13 & 18 Disorders

CHRONIC ENCEPHALITIS & EPILEPSY
See: Rasmussen Syndrome

CHRONIC FATIGUE SYNDROME

CFIDS Association of America
PO Box 220398
Charlotte, NC 28222-0398
(800) 442-3437
(704) 365-9755 (fax)
✉info@cfids.org
http://www.cfids.org
1,2,4,6,8

CHRONIC INFLAMMATORY DEMYELINATING POLYNEUROPATHY
See: Autoimmune Disorders

CHRONIC INFLAMMATORY DEMYELINATING POLYRADICULONEUROPATHY
See: Guillain-Barré Syndrome

CHRONIC LOCALIZED ENCEPHALITIS
See: Rasmussen Syndrome

CITRULLINEMIA
See: Urea Cycle Disorders

CLEFT PALATE
See also: Craniofacial Disorders

Cleft Palate Foundation
104 Estes Drive, Ste. 204
Chapel Hill, NC 27514
(800) 242-5338
(919)933-9044
(919)933-9604 (fax)
✉cleftline@aol.com
http://www.cleft.com
2,4,5,6,7; Spanish materials

CMV, CONGENITAL
See: Cytomegalovirus (CMV), Congenital

COBALAMIN (B12) DEFIENCY
See also: Metabolic Disorders

Cobalamin Network
PO Box 174
Thetford Center, VT 05075-0174
(802) 785-4029
✉suebee18@valley.net
3

COCKAYNE SYNDROME
See also: Growth Disorders; Xeroderma Pigmentosum

Share and Care Cockayne Syndrome Network
c/o Teresa Wall
PO Box 552
Stanleytown, VA 24168-0552
(540) 629-2369
(540) 647-3739 (fax)
✉cockayne@kimbanet.com
1,2,3,9;Spanish and Japanese materials

COFFIM-SIRIS' SYNDROME
See: Ectodermal Dysplasias

COFFIN-LOWRY SYNDROME

Coffin-Lowry Syndrome Foundation
13827 196th Ave. SE
Renton, WA 98059
(425) 204-9176
✉clsfoundation@yahoo.com
http://www.freeyellow.com/members/ clsf/ index.html
1,2,3,9

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COGAN'S SYNDROME
See: Autoimmune Disorders

COLITIS
See: Crohn Disease & Colitis

COLOBOMA
See: Visual Impairments

COMPLEX REGIONAL PAIN SYNDROME
See: Reflex Sympathetic Dystrophy Syndrome

CONGENITAL ADRENAL HYPERPLASIA (CAH)
See: Adrenal Disorders

CONGENITAL LIPOID HYPERPLASIA
See: Adrenal Disorders

CONGENITAL SENSORY NEUROPATHY WITH ANHIDROSIS
See: Familial Dysautonomia

CONNECTIVE TISSUE DISORDERS
See: Ehlers-Danlos Syndrome; Epidermolysis Bullosa, Dystrophic; Marfan Syndrome; Pseudoxanthoma Elasticum (PXE)

Coalition for Heritable Disorders of Connective Tissue
382 Main St.
Port Washington, NY 11050
(800) 862-7326
(516) 883-8712
(516) 883-8040 (fax)
✉staff@marfan.org
http://www.marfan.org
2,7

CONRADI-HÜNERMANN SYNDROME
See: Growth Disorders; Ichthyosis

COOLEY THALASSEMIA MAJOR
See also: Autoimmune Disorders

Cooley's Anemia Foundation
26th Ave. Ste. 203
Flushing, NY 11354
(800) 522-7222
(718) 321-2873
(718) 321-3340 (fax)
✉nacf@aol.com
http://www.thalassemia.org
1,2,3,4,5,6,7,8,9;
Italian,Greek,Chinese materials available in limited quanity

Thalassemia Action Group
12909 26th Ave, Ste. 203
Flushing, NY 11354
(800) 522-7222
(718) 321-2873
(718) 321-3340 (fax)
✉ncaf@aol.com
1,2,3,4,5,6,7,8,9

Thalassemia Foundation
32 Fern Ave.
Weston, Ontario CAN M9N 1M2
(416) 242-8425
✉josie.sima@utoronto.ca
1,2,3,4,5,6,8,9

COPPER DEFICIENCY, X-LINKED
See: Menkes Disease

COPPER MALABSORPTION, X-LINKED
See: Menkes Disease

CORI DISEASE
See: Glycogen Storage Diseases; Muscular Dystrophy

CORNELIA DE LANGE SYNDROME

Cornelia de Lange Syndrome Foundation
302 W. Main St. #100
Avon, CT 06001-3681
(800) 223-8355
(860) 676-8166
(860) 676-8337 (fax)
http://cdlsoutreach.org
✉cdlsintl@iconn.net

CORPUS CALLOSUM DISORDERS
See: Agenesis of the Corpus Callosum; Aicardi Syndrome

COX DEFICIENCY
See: Leigh Disease; Mitochondrial Disorders

CRANIOCARPOTARSAL DYSTROPHY
See: Freeman-Sheldon Syndrome

CRANIOECTODERMAL SYNDROME
See: Ectodermal Dysplasias

CRANIOFACIAL DISORDERS

AboutFace International
99 Crowns Ln., 4th Fl.
Toronto, ON CAN M5R 3P4
(800) 665-3223
(416) 944-3223
(416) 944-2488 (fax)
http://www.interlog.com/abtface
✉abtface@interlog.com
1,2,3,4,5,6,7

AboutFace USA
1407-1/2 N. wells
Chicago, IL 60610
(800) 665-FACE [3223]
(312) 337-0742
(312) 787-3136 (fax)
✉AboutFace2000@aol.com
1,2,3,4,5,6,7

Children's Craniofacial Association
PO Box 280297
Dallas, TX 75228
(800) 535-3643
(972) 994-9902
(972) 240-7607(fax)
http://www.masterlink.com\children
✉dnkm90@prodigy.com
1,2,3,4,5,6,9; Spanish materials, financial assistance for related expenses, annual family retreat

Craniofacial Foundation of America
c/o Terri Farmer
975 E. Third St.
Chattanooga, TN 37403
(800) 418-3223
(423) 778-9192
(423) 778-8172 (fax)
http://www.erlanger org/cranio
✉dnkm90@prodigy.com
1,2,3,5,7

FACES–The National Craniofacial Association
PO Box 11082
Chattanooga, TN 37401
(800) 332-2373
(423) 266-1632
(423) 267-3124 (fax)
✉Faces@mindspring.com
http://www.faces-cranio.org
1,2,3,6,9; financial assistance for medical-related travel

Forward Face: The Charity for Children with Craniofacial Conditions
Inst. of Reconstructive Plastic Surgery
317 34th St., Rm. 901A
New York, NY 10016
(800) 393-3223
(212) 684-5860
(212) 684-5864 (fax)
1,2,3,4

Let's Face It
PO Box 29972
Bellingham, WA 98228-1972
(360) 676-7325
✉letsfaceit@faceit.org
http://www.faceit.org/faceit/
1,3; Publishes annual resource guide

National Foundation for Facial Reconstruction
317 E. 34th St., Rm. 901
New York, NY 10016
(212) 263-6656
(212) 263-7534 (fax)
✉nffr@earthlink.net
http://www.nffr.org
2,3,4,8,9

CRANIOSYNOSTOSIS
See: Craniofacial Disorders

CRANIOSYNOSTOSIS
See: Craniofacial Disorders

CRI DU CHAT SYNDROME

5p- Society
PMB-502
7108 Katella
Stanton, CA 90680
(888) 970-0777
(714) 901-1544
(714) 890-9850
✉fivepminus@aol.com
http://www.fiveminus.org
1,2,3,6,7,9

CRIB DEATH
See: Sudden Infant Death Syndrome (SIDS)

CRIGLER-NAJJAR
See: Liver Disease and Trasplant

CROHN DISEASE & COLITIS

CCFA: Crohn's & Colitis Foundation of America
386 Park Ave. S., 17th Fl.
New York, NY 10016-8804
(800) 932-2423
(212) 685-3440
(212) 779-4098 (fax)
http://www.ccfa.org
✉info@ccfa.org
1,2,4,5,7,8; Spanish materials

Crohn's and Colitis Foundation of Canada
21 St. Clair Ave. E., Ste. 301
Toronto, ON CAN M4T 1L9
(800) 387-1479 (CAN only)
(416) 920-5035
(416) 929-0364 (fax)
http://www.ccfc.ca
✉ccfc@netcom.ca
1,2,5,6,8,9; French materials

Pediatric Crohn's & Colitis Association
PO Box 188
Newton, MA 02168
(617) 489-5854 (voice/fax)
1,2,3,4,7,8

CURLY HAIR-ANKYLOBLEPHARON-NAIL DYSPLASIA (CHANDS)
See: Ectodermal Dysplasias

CUSHING SYNDROME
See: Adrenal Disorders

CUTIS HYPERELASTICA
See: Ehlers-Danlos Syndrome

CUTIS LAXA
See: Connective Tissue Disorders

CYCLIC VOMITING SYNDROME

Cyclic Vomiting Syndrome Association
3707 Cedar Hill Rd., NW
Canal Winchester, OH 43110
(614) 837-2586
(614) 837-6543 (fax)
✉Drwaites@infinet.com
http://www.beaker.iupui.edu/cusa
1,2,3,4,5,6,8,9

CYSTIC FIBROSIS

Canadian Cystic Fibrosis Foundation
2221 Yonge St., Ste. 601
Toronto, ON CAN M4S 2B4
(800) 378-2233 (Canada only)
(416) 485-9149
(416) 485-0960 (fax)
✉info@ccff.ca
http://www.ccff.ca/~cfwww/index.html
1,2,5,6,7,8,9; French, German, Spainish, and Russian brochures and booklets. Videos avaliable in French and English

Cystic Fibrosis Foundation
National Office
6931 Arlington Rd.
Bethesda, MD 20814
(800) 344-4823 (301) 951-4422
(301) 951-6378 (fax)
http://www.cff.org
1,2,3,4,5,6,7,8,9

CYSTINOSIS
See also: Kidney Disorders

Cystinosis Foundation
2516 Stockbridge Dr.
Oakland, CA 94611
(800) 392-8458
(510) 482-8119
http://www.cystinosisfoundation.ucsd.edu
✉jd2jptz@qmis.net
1,2,3,6,7,8, Italian and French materials

CYSTINURIA
See also: Kidney Disorders

Cystinuria Support Network
21001 NE 36th St.
Redmond, WA 98053
(425) 868-2996
✉cystinuria@aol.com
1,3,9

CYTOCHROME C OXIDASE (COX) DEFICIENCY
See: Leigh Disease, Mitochondrial Disorders

CYTOMEGALOVIRUS (CMV), CONGENITAL

Clinical Care Center
CMV Registry, Ste. 150
1102 Bates St.
Houston, TX 77030-2399
(713) 770-4387
(713) 770-4347 (fax)
http://www.4cmv.com
✉cmv@bcm.tmc.edu
1,2,3,4

DANDY-WALKER SYNDROME
see also: Hydrocephalus

Dandy Walker Syndrome Network
5030 142nd Path W
Apple Valley, MN 55124
(612) 423-4008
2,3,4

DARIER DISEASE
See: Ichthyosis

DE BARSEY SYNDROME
See: Connective Tissue Disorders

DE BARSEY-MOENS-DIERCKS SYNDROME
See: Connective Tissue Disorders

DE MORSIER SYNDROME
See: Septo-Optic Dysplasia

DEAF-BLIND
See also: Hearing Impairments; Visual Impairments

American Association of the Deaf-Blind
814 Thayer Ave., Ste. 302
Silver Spring, MD 20910
(301) 588-6545 (TTY only)
(301) 588-8705 (fax)
1,2,6,7

National Family Association for Deaf-Blind
111 Middle Neck Rd.
Sand Point, NY 11050-1129
(800) 255-0411,Ext. 275
(516) 944-8637 (TTY)
(516) 944-7302 (fax)
✉hkncdir@aol.com
http://www.helenkeller.org.national
1,2,3,4,5,6; Newsletter available by request in braille, on disk (WP5.1) or large print.

The Canadian Deafblind and Rubella Association
c/o The W Ross Macdonald School
350 Brant Ave.
Brantford, ON CAN N3T 3J9
(519) 754-0729
(519) 754-5400 (fax)
1,2,7

DEAFNESS
See: Hearing Impairments

DEATH
See: Bereavement Support

DEBRANCHER ENZYME DEFICIENCY
See: Glycogen Storage Diseases; Muscular Dystrophy

DECARBOXYLICACIDURIA
See: Fatty Oxidation Disorder

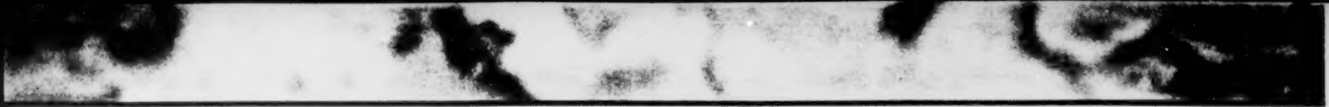
DECEREBRATE DEMENTIA
See: Subacute Sclerosing Panencephalitis

DEJERINE SOTTAS DISEASE
See: Muscular Dystrophy

DEJERINE-LANDOUZY
See: Muscular Dystrophy; Facio-Scapulo-Humeral

DELTA STORAGE POOL DISEASE
See: Hermansky-Pudlak Syndrome

DENTOOCULOCUTANEOUS SYNDROME
See: Ectodermal Dysplasias



DERMATITIS HERPETIFORMIS
See: Celiac Disease; Celiac Sprue; Gluten Intolerance

DERMATOCHALASIA
See: Connective Tissue Disorders

DERMATOLYSIS
See: Connective Tissue Disorders

DERMATOMEGALY
See: Connective Tissue Disorders

DERMATOMYOSITIS
See: Arthritis; Muscular Dystrophy; Myositis

DERMOODONTODYSPLASIA
See: Ectodermal Dysplasias

DERMOTRICHIC SYNDROME
See: Ectodermal Dysplasias

DEVELOPMENTAL DISABILITIES
See: Mental Retardation

DIABETES INSPIDUS
See also: Autoimmune Disorders

The Diabetes Insipidus Foundation Inc.
4533 Ridge Dr.
Baltimore, MD 21229
(410) 247-3953
1,2

DIABETES MELLITUS
See also: Autoimmune Dosorderd; Kidney Disorders

American Diabetes Association
National Service Ctr.
1660 Duke St.
Alexandria, VA 22314
(800) 342-2383
(703) 549-1500
(703) 549-6995 (fax)
http://www.diabetes.org
1,2,4,5,6,7,8

DIABETES MELLITUS
See also: Kidney Disorders

Canadian Diabetes Association
15 Toronto St., Ste. 800
Toronto, ON CAN M5C 2E3
(416) 363-3373
(416) 363-3393 (fax)
✉info@diabetes.ca
1,2,4,6,7,8; French Materials

DIGESTIVE DISORDERS
See: Celiac Disease; Celiac Sprue; Crohn Disease & Colitis; Gluten Intolerance; Intestinal Pseudo-Obstruction Syndrome; Ostomy

DIGESTIVE DYSMOTILITY
See: Intestinal Pseudo-Obstruction Syndrome

DIMORSIER SYNDROME
See: Growth Disorders

DISCOID LUPUS
See: Autoimmune Disorders

DOWN SYNDROME

Association for Children with Down Syndrome
2616 Martin Ave.
Bellmore, NY 11710
(516) 221-4700
(516) 221-5867 (fax)
1,2,3,4, bilingual services

Canadian Down Syndrome Society
811 14th St. NW
Calgary, AB CAN T2N 2A4
(800) 883-5608 (in Canada)
(403) 270-8500
(403) 270-8291 (fax)
✉cdss@ican.net
http://home.ican.net/~cdss
1,2,3,4,6,7,8,9,10,11; French materials

Down Syndrome Society of Rhode Island
99 Bald Hill Rd.
Cranston, RI 02920
✉dssri@aol.com
1,2,3,5,6

Foundation for Children with Down Syndrome
17646 N. Cave Creek Rd., Ste. 152
Phoenix, AZ 85032
(612) 822-3724
(612) 822-3734 (fax)
http://www.ffcwds.org

Foundation for Children with Down Syndrome (NJ office)
355 Bennetts Mills Rd.
Jackson, NJ 08527
(718) 623-0121

International Foundation for Genetic Research
500A Garden City Dr.
Pittsburgh, PA 15146
(412) 823-6380
(412) 373-7713 (fax)
✉tmf@pennet.com
http://www.pennet.com/chuckdet/index.html
1,2,4,7,8

National Down Syndrome Congress
7000 Peachtree
Donwoddy Road, Building 5,Ste. 100
Atlanta, GA 30328
(800) 232-6372
(770) 604-9500
(770) 604-9898 (fax)
✉ndfccenter@aol.com
http://www.ndfccenter.org
1,2,3,4,6,7

National Down Syndrome Society
666 Broadway, 8th Fl.
New York, NY 10012-2317
(800) 221-4602
(212) 460-9330
(212) 979-2873 (fax)
http://www.ndss.org
✉info@ndss.org
1,2,4,5,6,7,8

Trisomy 21 Reseearch Foundation
933 First Colonial Rd, Ste. 109
Virginia Beach, VA 23454
(757) 425-1969
(757) 425-1822 (fax)
http://wwwtri21.org
✉illeichtman@macs.net
2,4,7,8,9

DUAL SENSORY IMPAIRMENTS
See: Deaf-Blind

DUBOWITZ SYNDROME
See also: Craniofacial Disorders; Growth Disorders

Dubowitz Syndrome Parent Support Network
PO Box 2441
Vincennes, IN 47591
(812) 886-0575
(812) 886-1128 (fax)
http://dubowitz.org
✉INATTIC1@aol.com

DUCHENNE MUSCULAR DYSTROPHY
See: Muscular Dystrophy

DWARFISM
See also: Growth Disorders; Short Stature

Billy Barty Foundation
3393 Geneva Dr.
Santa Clara, CA 95051
(408) 244-6354
(408) 296-6317
✉figone@netgate.net
1,2,3,4,5,6,7; emergency financial assistance, scholarships

DYGENESIS OF THE CORPUS CALLOSUM
See: Agenesis of the Corpus Callosum

DYSAUTONOMIA, FAMILIAL
See: Familial Dysautonomia

DYSKERATOSIS, CONGENITAL
See: Ectodermal Dysplasias

DYSLEXIA
See also: Attention Deficit Disorder; Learning Disabilities

Dyslexia Research Institute
5746 Centerville Rd.
Tallahassee, FL 32308
(850) 893-2216
(850) 893-2440 (fax)
✉dri@talstar.com
http://www.dyslexia-add.org
2,3,4

The International Dyslexia Association
8600 La Salle Rd.
Chester Bldg., Ste. 382,
Baltimore, MD 21286-2044
(800) 222-3123,
(410) 296-0232,
(410) 321-5069 (fax)
✉info@interdys.org
http://www.interdys.org
1,2,3,4,5,6,7,8,9; Spanish materials

Recording for the Blind & Dyslexic
20 Roszel Rd.
Princeton, NJ 08540
(609) 452-0606,
(609) 520-7990 (fax)
2; Extensive lending library of academic textbooks on audiocassette (all levels)

DYSOSTOSIS, ACROFACIAL, NAGER TYPE
See: Nager & Miller Syndromes

DYSOSTOSIS, MANDIBULOFACIAL
See: Nager & Miller Syndromes; Treacher Collins Syndrome

DYSOSTOSIS, METAPHYSEAL, TYPE B IV
See: Shwachman Syndrome

DYSOSTOSIS, POSTAXIAL ACROFACIAL
See: Nager & Miller Syndromes

DYSPLASTIC ANGIECTASIA, CONGENITAL
See: Klippel-Trenaunay Syndrome

DYSTONIA

Dystonia Medical Research Foundation
One E Wacker Dr., Ste. 2430
Chicago, IL 60601-1905
(312) 755-0198
(312) 803-0138 (fax)
http://www.dystonia-foundation.org/
✉dystonia@dystonia-foundation.org/
1,2,3,4,5,6,7,8,9

Dystonia Medical Research Foundation—Canada
116-230 Heath St. W.
Toronto, ON CAN M5P 1N8
(800) 361-8061 (Canada only)
(416) 487-8326
✉Dystonia@Dystonia-foundation.org
1,2,3,4,5,7,8,9

DYSTROPHIC EPIDERMOLYSIS BULLOSA
See: Epidermolysis Bullosa, Dystrophic

EATON-LAMBERT SYNDROME
See: Muscular Dystrophy

ECTODERMAL DYSPLASIAS

Canadian Society for Ectodermal Dysplasia (Western Canada)
304 Hawkwood Blvd., NW
Calgary, AB CAN T3G 2Y5
(416) 664-6121
2,3,4

Canadian Society for Ectodermal Dysplasia (Eastern Canada)
232 MacIntosh Dr.
Stoney Creek, ON CAN L8E 4C2
(905) 664-6121 (wrong number)
2,3,4,9

National Foundation for Ectodermal Dysplasia
410 E. Main St.
PO Box 114
Mascoutah, IL 62258-0114
(618) 566-2020
618-566-4718
http://www.nfed.org
nfed1@aol.com
1,2,3,4,6,7,8,9

ECTRODACTYLY-ECTODERMAL DYSPLASIA-CLEFT LIP/PALATE (EEC) SYNDROME
See: Cleft Palate; Craniofacial Disorders; Ectodermal Dysplasias

EEC SYNDROME
See: Cleft Palate; Craniofacial Disorders; Ectodermal Dysplasias

EHLERS-DANLOS SYNDROME
See also: Connective Tissue Disorders; Glaucoma; Visual Impairments

Ehlers-Danlos National Foundation
6399 Wilshire Blvd. #510
Los Angeles, CA 90048
(323) 651-3038,
(323) 651-1366(fax)
✉LooseJoints@aol.com
http://www.ednf.org
1,2,3,4,6,8

EINSTEIN SYNDROME
See: Hearing Impairments; Kidney Diseases, Hereditary; Vision Impairments

ELASTORRHEXIS
See: Connective Tissue Disorders

ELASTOSIS DYSTROPHICA SYNDROME
See: Pseudoxanthoma Elasticum (PXE)

ELEPHANTITIS
See: Lymphedema

ELLIS-VAN CREVELD SYNDROME
See: Ectodermal Dysplasias

EMERY-DREIFUSS MUSCULAR DYSTROPHY
See: Muscular Dystrophy

EMG SYNDROME
See: Beckwith-Wiedemann Syndrome

ENCEPHALITIS, CHRONIC LOCALIZED
See: Rasmussen Syndrome

ENCEPHALITIS & EPILEPSY, CHRONIC
See: Rasmussen Syndrome

ENCEPHALITIS, RASMUSSEN
See: Rasmussen Syndrome

ENCEPHALOFACIAL ANGIOMATOSIS
See: Sturge-Weber Syndrome

ENCEPHALOMYELOPATHY
See: Leigh Disease

ENCEPHALOMYELORADICULOPATHY, ACUTE ISSEMINATED
See: Guillain-Barré Syndrome

ENCEPHALOTRIGEMINAL ANGIOMATOSIS
See: Sturge-Weber Syndrome

ENCHONDROMATOSIS
See: Ollier Disease

ENDOCARDIAL FIBROSLASTOSIS
See: Heart Disorders

ENTEROPATHY, GLUTEN-SENSITIVE
See: Celiac Disease; Celiac Sprue; Gluten Intolerance

EOSINOPHILIC GRANULOMA
See: Histiocytosis

EPICANTHUS INVERSUS
See: Blepharophimosis, Ptosis, Epicanthus Inversus Syndrome (BPES)

KEY TO SERVICES

1 Periodical/newsletter
2 Informational materials
3 Networking/matching
4 Referrals to local resources
5 Local chapters
6 National conferences
7 National advocacy efforts
8 Fund research
9 Maintain research registry

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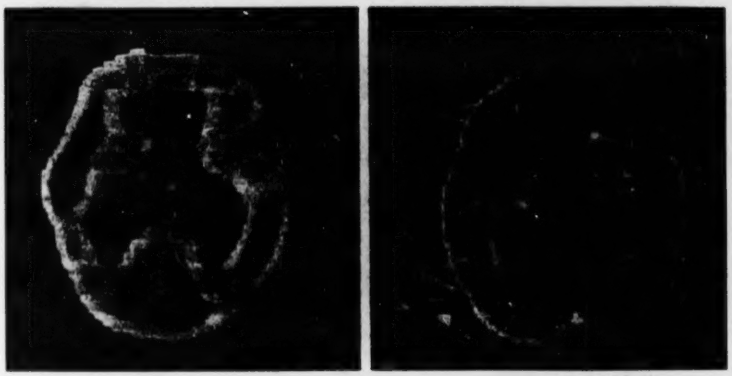

Before *After*
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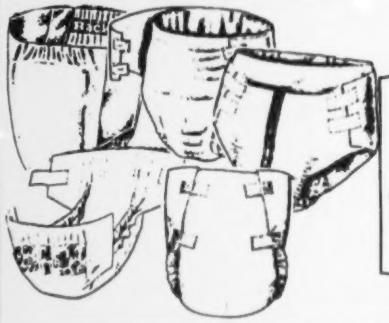

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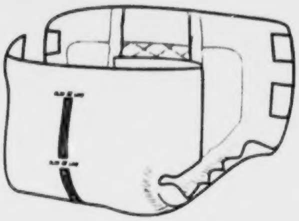

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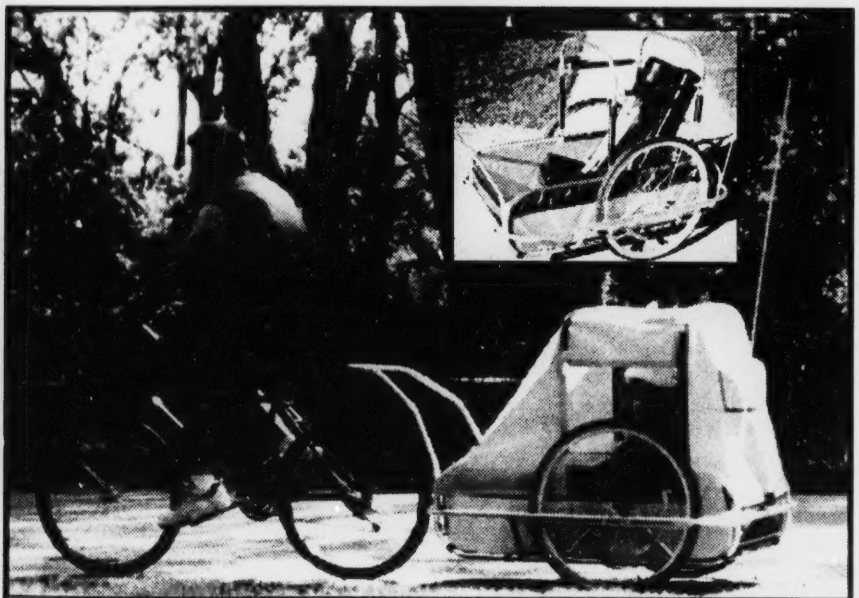

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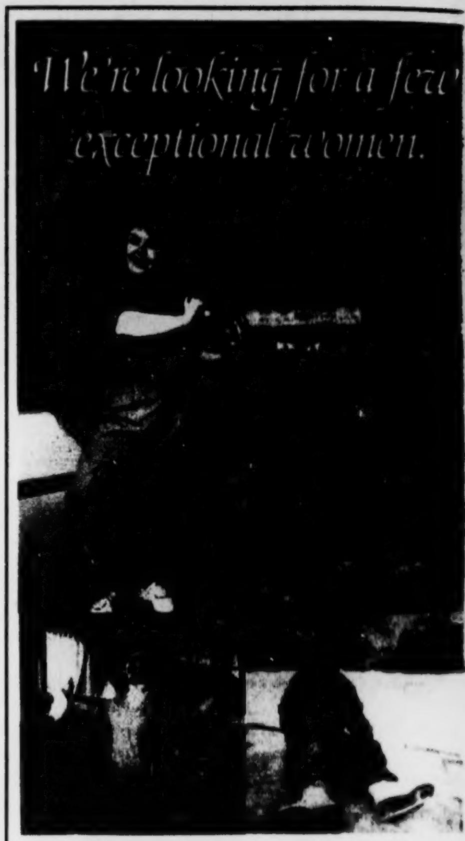
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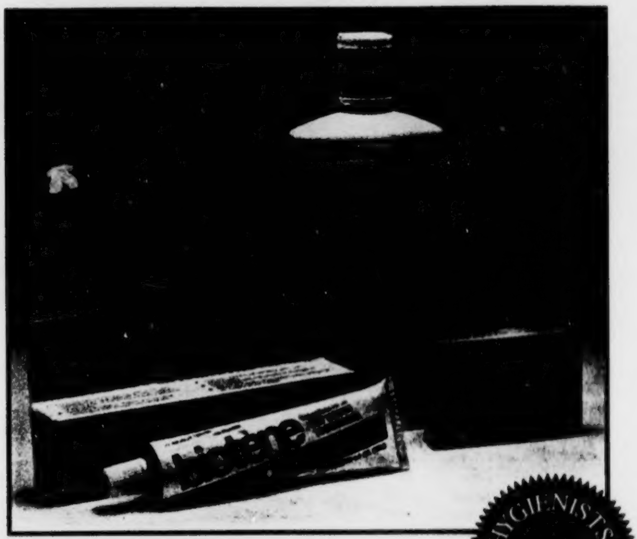

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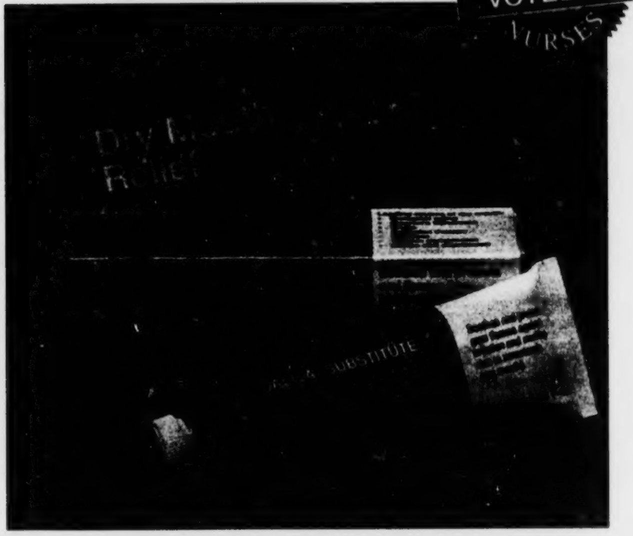

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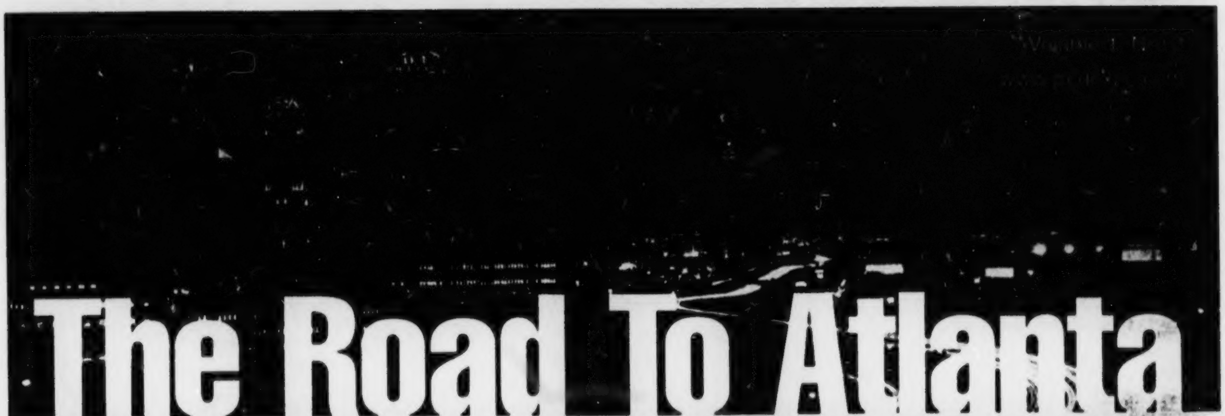

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Sigma-Tau Pharmaceuticals is guided by the principle that no patient should ever be overlooked, no matter how rare his or her disorder. Sigma-Tau places great emphasis on fully understanding metabolic disorders and on developing products for these conditions and other rare or less known disorders. We believe that patients shouldn't have to worry about where their next medication will come from - or if they'll get the right treatment. No matter how small the patient population, we endeavor to foster consumer knowledge about and comfort with the use of our products.

Sigma-Tau works hard to put a face on unmet medical needs and to maintain strong partnerships with healthcare professionals in order to provide resources that can help answer difficult questions about metabolic disorders and commonly misdiagnosed diseases. Sigma-Tau is a leader in patient and physician education and awareness campaigns to address childhood diseases that are commonly characterized by misdiagnosis (an incorrect diagnosis) or missed diagnosis (no diagnosis).

"Sigma-Tau Pharmaceuticals is pleased to be a founding sponsor of the first World Congress & Exposition on Disabilities," says Kenneth Mehrling, Executive Vice President. "We feel that this is a tremendously valuable forum in which patients, families, physicians and associations can come together to share information and provide benefits to those with disabilities. We are proud to be part of this event because it supports Sigma-Tau's goal to help ensure that no patient is overlooked."

Among the products that Sigma-Tau develops and produces are orphan drugs – drugs with a treatment population of fewer than 200,000 patients. For example, Sigma-Tau offers Carnitor® (levocarnitine), the only prescription form of levocarnitine available for the treatment of carnitine deficiency. As many as 375,000 people suffer from various metabolic abnormalities, which may cause carnitine deficiency – a condition that can be difficult to diagnose since its symptoms often mimic those of other disorders.

Always mindful of helping patients gain access to needed drugs, Sigma-Tau funds patient assistance programs through the National Organization for Rare Disorders (NORD) for its prescription products to help ensure that underinsured and financially needy patients receive the products at no cost. These kinds of programs help to keep us in constant contact with the communities we serve and help us to make sure that no patient is overlooked. We are proud to work with many medical and patient advocacy groups, community organizations and research foundations, including NORD, the National Kidney Foundation, the United Mitochondrial Disease Foundation, the Epilepsy Foundation, the Child Neurology Society, the American Academy of Pediatrics and others.

For more information about Sigma-Tau, visit the Sigma-Tau website at www.sigma-tau.com or call 800-447-0169.

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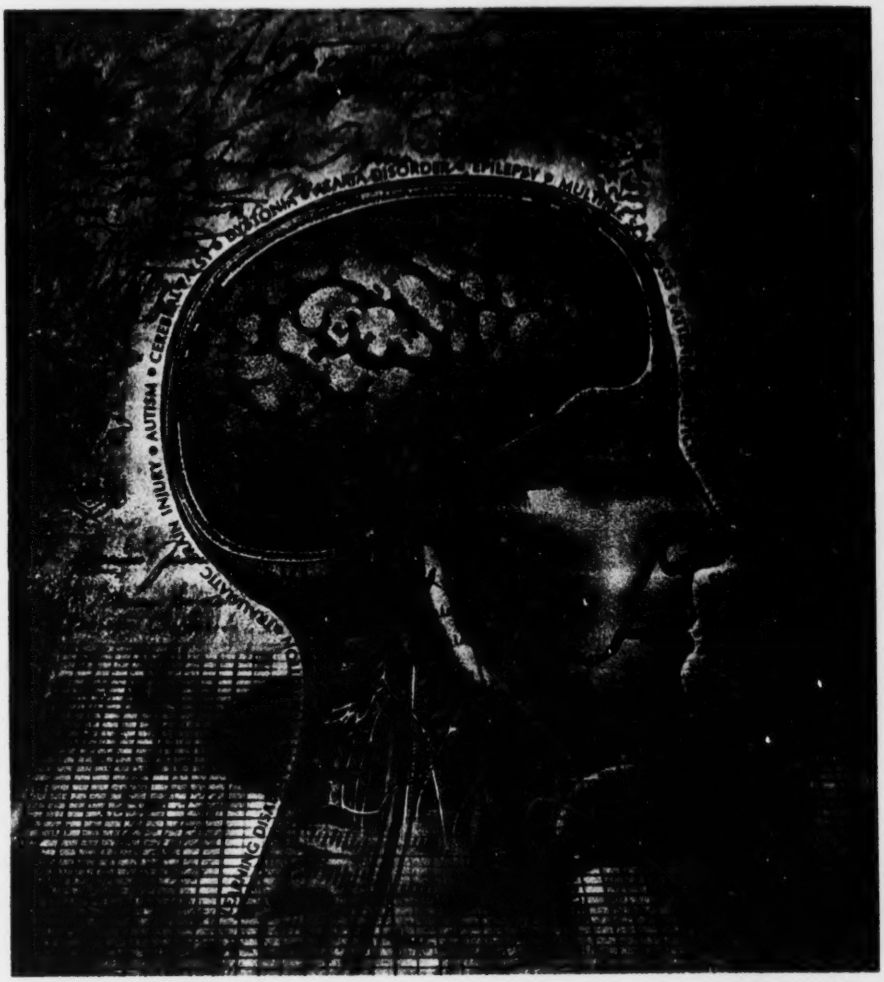

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Exposition on Disabilities

The first international forum of "information that matters from people who care" for people who care: families and professionals in science, medicine, education and advocacy.

November 10-12, 2000, Atlanta, Georgia

Exceptional Parent Magazine and H.A. Bruno, LLC invite families of people with disabilities and professionals from the fields of healthcare and education from across the United States, Canada and around the world to share information, strategies, experiences, ideas and innovations.

A World-Class Weekend

Join forces and voices for people with disabilities

For Families and Caregivers: Experienced parents and professionals share first-hand, hands-on and first-person strategies and techniques for planning and problem solving in the home, the family, the community and the world at large. 400 associations are invited to share programs, projects and advocacy ideas.
Agenda items: insurance, schools, recreation, estate-planning, health care providers, employment, assessibility, technology, and many more.

For Physicians, Physical Therapists, Occupational Therapists and Educators: International experts discuss movement and brain disorders in symposia, lecture and workshop settings. Emory University's School of Medicine provides CME and CEU credits and administers a call for papers. X professional associations are also invited.
Agenda items: ataxias, spasticity, Tourette, Parkinson's, epilepsy, AD/HD, newborn screening for inborn metabolic errors, mitochondrial diseases, infant nutrition, learning disabilities, and many more.

For Those with Disabilities: Opportunities for information and hands-on introductions to the latest innovations in technology, health care, fun and advocacy.
Agenda items: Free dental and vision screening, hands-on workshops in technology and educational software, sports and recreation pavilion, Career Fair featuring live interviews with major corporations, the best toys, games and videos for fun and educational use and many more.

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International Conference & Exposition on Disabilities Is Aimed at Both Professionals and Consumers

The World Congress & Exposition on Disabilities will take place November 10-12, 2000 at the Georgia International Convention Center in Atlanta. This precedent-setting conference and trade show is the first in what will be an annual event designed to educate, inform and provide a useful exchange of ideas for persons with disabilities and special health care needs, as well as for those involved in their care and development. Supported by the National Institutes of Health, several leading corporations and national associations and organizations, the event is being produced by H.A. Bruno, LLC in conjunction with Exceptional Parent magazine.

Opinion leaders in science, medicine, research, technology and product development are expected to gather along with caregivers and families for an intensive learning experience focused on the needs of all people with disabilities. Symposiums, seminars and workshops during the conference will offer professional participants CME (Continuing Medical Education) and CEU (Continuing Educational Units) accreditation through Emory University.

Uniting professional and consumer interests within one conference is a logical extension of the current health care climate, says Exceptional Parent magazine President, CEO and Publisher Joseph Valenzano. "Increasingly, families and other caregivers are becoming extraordinarily well informed about all aspects of dealing with healthcare issues, especially those related to people with disabilities. They're putting together arsenals of knowledge with which to advocate and ensure the best care, treatment and advancement for people with disabilities and special health care needs," he says.

The initial conference will feature world experts in such areas as neurology, mitochondrial and metabolic disorders, end stage renal disease, nephrology, attention deficit and hyperactivity disorders, seizure disorders such as epilepsy, nutrition, learning disabilities and movement disorders such as the ataxia's, spasticity, tourettes, the dystonias and parkinson's.

In addition to scheduled educational programs, the event will provide an opportunity to examine the latest products and services from hundreds of exhibitors. These will include representatives of the pharmaceutical, computer, automotive, mobility, personal care and travel industries, along with those associated with nutrition, communication, estate and financial planning, insurance and publishing.

Please send me information on the World Congress & Exposition on Disabilities, November 10- 12, 2000 at the Georgia International Convention Center in Atlanta

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City State Zip Code

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*Shown with optional ventilator tray, and oxygen holder

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The satisfaction I receive upon the successful conclusion of a cerebral palsy case is immeasurable. Knowing that I have contributed to the security and future well being of a special person is the most important part of my job.

UNIQUE ATTRIBUTES

My son was born with brain damage, so I have first hand experiences and feelings to guide me when discussing your case. My family and I have become very involved with persons having all types and levels of disabilities. As an example, my wife is president of The Womens Board at Lambs Farm, a residential community for the developmentally disabled. We all volunteer frequently in many capacities there. We also support other foundations that are concerned with the betterment of special people. Our personal and professional lives revolve around persons with disabilities. We strive to bring fulfillment to the lives of our special friends. They deserve everything in life that we have, and more!

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Dear Parents:

When my son was born with brain damage, my family and I had no idea how our lives would be affected. We did not see how vulnerable our child was and how he would need our care and protection for the rest of his life. We did not understand that we would become his life-line in so many ways, and he in turn would consume our lives.

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We would be interested in looking into your child's birth if you had complications either during pregnancy, during delivery, or after delivery.

Please call 1-800-888-LAWS and speak with either an attorney or a registered nurse.

Remember, there are time restrictions.

Sincerely,

Sheldon O Zisook

Sheldon O. Zisook
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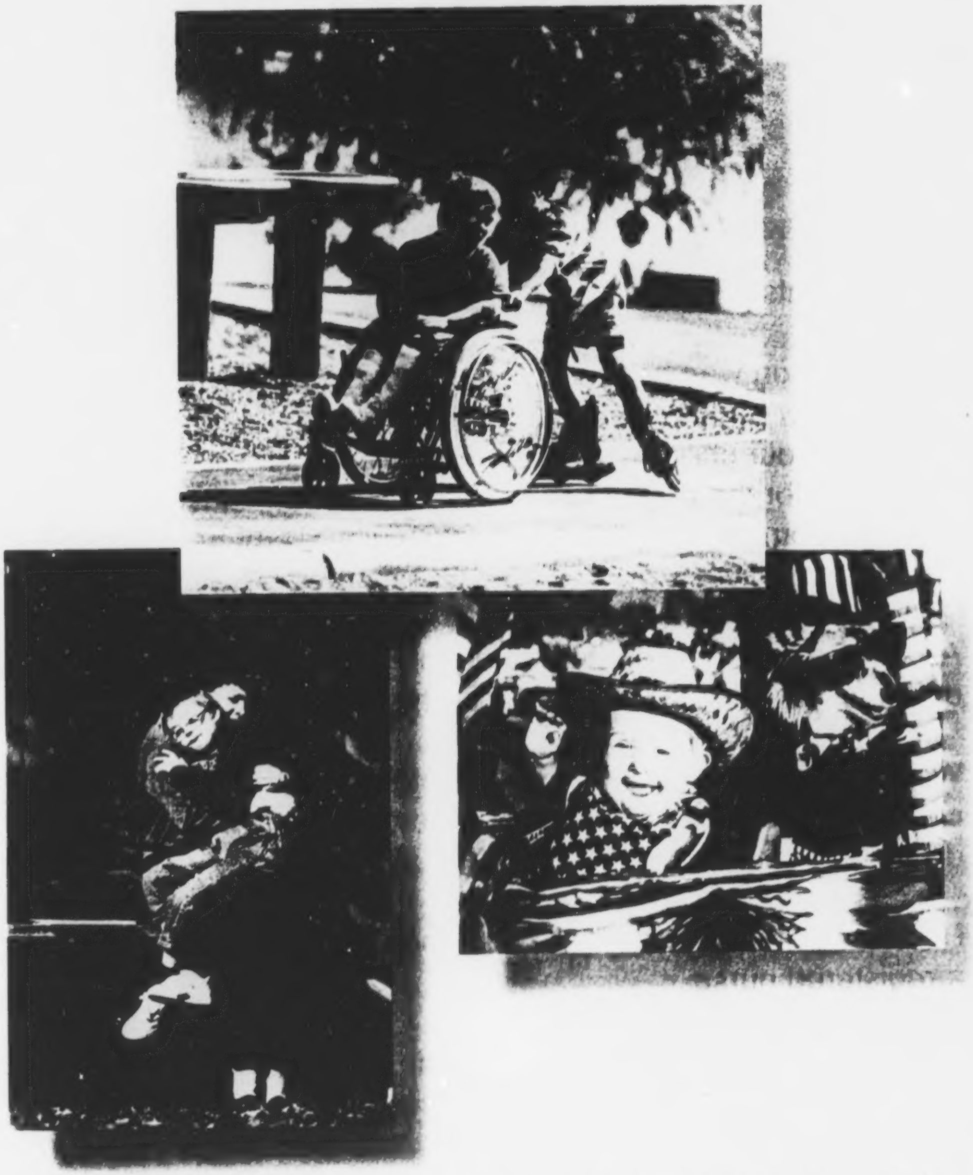
Circle #78

It takes more than love to secure your child's future. It takes careful planning.



As a parent, you do everything you can to help ensure that your child enjoys a comfortable and meaningful life. This should include addressing unique planning needs for your child's future.

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- *Day and nighttime protection*
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- *Tear-away sides for easy removal*
- *Three sizes, to fit kids from 45–125 lbs.*

Imagine your child gaining a little more independence just by a change in clothing. For information on how GoodNites can help, please visit us at www.goodnites.com

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National Resources for Specific Disabilities

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New York, NY 10006
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(212) 513-4099
http://www.debra.org
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See: Ichthyosis

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Hartford, CT 06105-4240
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(860) 586-7550 (fax)
http://www.aesnet.org
✉info@aesnet.org
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1470 Peel St., Ste. 745
Montreal, PQ CAN H3A 1T1
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Landover, MD 20785-2267
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(301) 459-3700
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See: Histiocytosis

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Evans Syndrome Support and Research Group
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Port Orange, FL 32127
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(904) 760-5583 (fax)
73142.1315@compuserve.com
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International Center for Fabry Disease
Dept of Human Genetics
Mt Sinai School of Medicine
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PO Box 1497
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(212) 241-6944
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http://www.fshsociety.org
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See: Anemia, Fanconi

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See: Fetal Alcohol Syndrome/Effect

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See also: Metabolic Disorders

Support Group for FOD Families
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Greensboro, NC 27410
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✉FODgroup@aol.com
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FEMALE SEX CHROMOSOME DISORDERS
See: Turner Syndrome

FETAL ALCOHOL SYNDROME/EFFECT

Family Empowerment Network: Supporting Families Affected by FAS/FAE
517 Lowell Center
610 Langdon St.
Madison, WI 53703
(800) 462-5254
(608) 262-6590
(608) 265-3352 (fax)
✉fen@mail.dcs.wisc.edu
1,2,3,4,6,7; Spanish materials

Fetal Alcohol Education Program
1975 Main St.
Concord, MA 01742
(508) 369 -7713
2,3,4,9

National Organization on Fetal Alcohol Syndrome
418 C St. NE
Washington, DC 20002
(800) 66NOFAS (information line)
(202) 785-4585
(202) 466-6456 (fax)
http://www.nofas.org
✉nofas@erols.com
1,2,4; available in English and Spanish

Support and Education Network for FAS Parents and Caregivers
c/o Bergen County Council on Alcoholism & Drug Abuse, Inc.
PO Box 626
Paramus, NJ 07653
(201) 261-2183
(201) 261-0807 (fax)
2,3; group includes many foster/adoptive parents, and some biological parents/caregivers

The Fetal Alcohol Syndrome Family Resource Institute
PO Box 2525
Lynnwood, WA 98036
(800) 999-3429
(253) 531-2878
(253) 531-2668 (fax)
http://www.accessone.com/~delindam/
✉vicfas@hotmail.com
1,2,3,4,5,6,9

Fetal Alcohol Support Network
2266 Homeland Dr.
Mississauga, ON CAN L5K 1G6
(905) 822-0733 (voice/fax)
1,2,3,4,9

FETAL FACE SYNDROME
See: Robinow Syndrome

FETAL IRITIS SYNDROME
See: Norrie Disease

FIBROMYALGIA
See: Arthritis

FIBROUS ANKYLOSIS OF MULTIPLE JOINTS
See: Arthrogryposis Multiplex Congenita

FIBROUS DYSPLASIA, MONOSTOTIC
See: McCune-Albright Syndrome

FIBROUS DYSPLASIA, POLYOSTOTIC
See: McCune-Albright Syndrome

FIBULAR HEMIMELIA
See: Limb Disorders

FIRST AND SECOND BRANCHIAL ARCH SYNDROME
See: Goldenhar Syndrome

FISCHER SYNDROME
See: Guillain-Barré Syndrome

FISCHER-JACOBSEN-CLOUSTON SYNDROME
See: Ectodermal Dysplasias

FOCAL DERMAL HYPOPLASIA (FDH) SYNDROME
See: Craniofacial Disorders; Ectodermal Dysplasias; Hearing Impairments

FOLATE METABOLISM; INBORN ERROR OF
See: Cobalamin (B12) Defiency

FOOD ALLERGY
See also: Asthma & Allergy

The Food Allergy Network
10400 Eaton Pl., Ste. 107
Fairfax, VA 22030-2208
(800) 929-4040
(703) 691-2713 (fax)
http://www.foodallergy.org
✉fan@worldweb.net
1,2,4,5,6,7,9;

FORBES DISEASE
See: Glycogen Storage Diseases; Muscular Dystrophy

FRAGILE X SYNDROME
See also: Attention Deficit Disorder; Autism; Learning Disabilities

FRAXA Research Foundation
45 Pleasant St.
Newburyport, MA 01950
(978) 462-1866
(978) 463-9985 (fax)
info@fraxa.org
✉http://www.fraxa.org
1,2,3,5,7,8,9; Internet mailing list

National Fragile X Foundation
1441 York St., Ste. 303
Denver, CO 80206
(800) 688-8765
(303) 333-6155
(303) 333-4369 (fax)
http://www.infxf.org
✉natfragx@ix.netcom.com
1,2,3,4,5,6,7,8,9

FRANCHESCHETTI-KLEIN SYNDROME
See: Treacher Collins Syndrome

FRAXA
See: Fragile X Syndrome

FREDREICH DISEASE
See: Ataxia; Friedreich Ataxia

FREDREICH TABES
See: Ataxia; Friedreich Ataxia

FREEMAN-SHELDON SYNDROME
See also: Craniofacial Disorders

Freeman-Sheldon Parent Support Group
509 E. Northmont Wy.
Salt Lake City, UT 84103
(801) 364-7060
http://www.fspsg.org
✉fspsg@aol.com
1,2,3,,9

FRIEDREICH ATAXIA
See also: Ataxia; Muscular Dystrophy

Canadian Association of Friedreich's Ataxia
5620 C A Jobin St.
Montreal, Quebec CAN H1P 1H8
(514) 321-8684
(514) 321-9257 (fax)
http://www.cam.org/~acaf
1,2,8,9; French materials

FUCOSIDOSIS
See: Tay-Sachs Disease

FULLER-ALBRIGHT SYNDROME
See: McCune-Albright Syndrome

FULMINATING HYPERPYREXIA
See: Malignant Hyperthermia

G SYNDROME
See: Opitz Syndrome

GALACTOSE-1-PHOSPHATE URIDYL TRANSFERASE DEFICIENCY
See: Galactosemia

GALACTOSEMIA
See also: Metabolic Disorders, Liver Disease

Parents of Galactosemic Children Inc.
2148 Bryton Dr.
Powell, OH 95252
(614) 840-0473
http://www.galactosemia.org
✉gayled3@aol.com
1,2,3,6,9

GARDNER SYNDROME
See: Peutz-Jeghers Syndrome; Polyposis

GASTROESOPHAGEAL REFLUX
See also: Intestinal Pseudo-Obstruction Syndrome

Gastroesophageal Reflux (GER) Pediatric/Adolescent Gastroesophageal Reflux Association Inc. (PAGER)
PO Box 1153
Germantown, MD 20875-1153
(301) 601-9541
✉gergroup@aol.com
http://www.reflux.org
1,2,3,5,6,9

GASTROINTESTINAL CANCER
See: Peutz-Jeghers Syndrome; Polyposis

GASTROINTESTINAL DISORDERS

The Oley Foundation
214 Hun Memorial
Albany Medical Center, A-23
Albany, NY 12208-3478
(800) 776-OLEY (6539)
(518) 262-5079
(518) 262-5528 (fax)
http://www.wizvax.net/oleyfdn
✉joan_bishop@ccgateway.amc.edu

GAUCHER DISEASE
See also: Tay-Sachs Disease

National Gaucher Foundation
11140 Rockville Pike, Ste. 350
Rockville, MD 20852-3106
(800) 925-8885
(301) 816-1515
(301) 816-1516 (fax)
http://www.gaucherdisease.org
✉ngf@gaucherdisease.org
1,2,3,4,5,6,7,8,9

GENEE-WIEDEMANN SYNDROME
See: Nager & Miller Syndromes

GENETIC DISORDERS

Alliance of Genetic Support Groups
4301 Conneticut Ave. NW, Ste. 404
Washington, DC 20008-2304
(202) 966-5557
(202) 966-8553 (fax)
(800) 336-GENE (4363) helpline
✉info@geneticalliance.org
http://www.geneticalliance.org
1,2; Spanish materials.

Association of Genetic Support/Australia AGSA
66 Albion St,
Surry Hills, Australia NSW 2010
(02) 9211 1462,
(02) 9211 8077 (fax)
1,2,3,4,6,9

Northeast VCFS Support Group
2 Lansing Dr.
Salem, NH 03079
(603) 898-6332
(603) 898-0705 (fax)
✉MLADJA@aol.com
http://www.vcfsef.org
1,2,3,6,9

GENITALIA, AMBIGUOUS
See also: Hermaphroditism

Ambiguous Genitalia Support Network (AGSN)
PO Box 313
Clements, CA 95227-0313
(209) 727-0313 (voice/fax)
✉agsn@jps.net
1,2,3,4,5,7,9

GILFORD SYNDROME
See: Progeria

GINGIVAL FIBROMATOSIS AND HYPERTRICHOSIS
See: Ectodermal Dysplasias

GIROUX-BARBEAU SYNDROME
See: Ichthyosis

GLAUCOMA
See also: Visual Impairments

Glaucoma Research Foundation
200 Pine Street
San Francisco, CA 94104
(800) 826-6693
(415) 986-3162
http://www.glaucoma.org
✉info@glaucoma.org
1,2,3,4,8; Spanish brochures available.

GLUCOSYL CEREBROSIDE LIPIDOSIS
See: Gaucher Disease

GLUTARIC ACIDURIA, TYPE I
See also: Acidemia, Organic; Lactic Acidosis

International Organization for Glutaric Aciduria, Type I
c/o Mike Metil and Cay Welch
RD 3, Box 167A
Jersey Shore, PA 17740
(570) 321-6487
1,2,3,4,6,8

GLUTARICACIDURIA I
See: Glutaric Aciduria, Type I

GLUTARICACIDURIA II
See: Acidemia, Organic; Lactic Acidosis

GLUTEN INTOLERANCE
See also: Celiac Disease; Celiac Sprue

Gluten Intolerance Group of North America
15110 Tenth Ave SW, Ste. A
Seattle, WA 98116-1820
(206) 246-6652,
(206) 246- 6531 (fax)
http:www.gluten.net
✉gig@accessone.com
1,2,3,4,6,7; Spanish materials

GLUTEN-SENSITIVE ENTEROPATHY
See: Celiac Disease; Celiac Sprue; Gluten Intolerance

GLYCOGEN STORAGE DISEASES
See also: Hypoglycemia

Association for Glycogen Storage Disease
PO Box 896
Durant, IA 52747
(319) 785-6038 (voice/fax)
1,2,3,4,7,9

GLYCOGENOSES
See: Glycogen Storage Diseases

GLYCOSPHINGOLIPIDOSES
See: Tay-Sachs Disease

GOLDENHAR SYNDROME
See also: Craniofacial Disorders

Goldenhar Syndrome Research & Information Fund
PO Box 61643
St. Petersburg, FL 33714
(813) 522-5772
(813) 522-5885 (fax)
http://www.GOLDENHAR.com
✉btorman@pbsnet.com
2

GOLDENHAR-GORLIN SYNDROME
See: Goldenhar Syndrome

GOLDFLAM DISEASE
See: Myasthenia Gravis

GONADAL DYGENESIS (45, X)
See: Turner Syndrome

GORLIN-CHAUDHRY-MOSS SYNDROME
See: Ectodermal Dysplasias

GRANULOMA, EOSINOPHILIC
See: Histiocytosis

GRANULOMATOUS DISEASE, CHRONIC
See also: Immune Disorders

Chronic Granulomatous Disease Association Inc.
c/o Mary Hurley
2616 Monterey Rd.
San Marino, CA 91108
(626) 441-4118
http://www.pacific.net.net/amhurley
✉amhurlley@pacific.net
1,2,3,4,7,9

GRAVES DISEASE
See: Thyroid Disorders

GROENBLAD-STRANDBERG SYNDROME
See: Pseudoxanthoma Elasticum (PXE)

GROUP B STREP

Group B Strep Association
PO Box 16515
Chapel Hill, NC 27516
(919) 932-5344 (voice)
(919) 932-3657 (fax)
http://www.groupbstrep.org
1,2,3,4,7,8,9

GROWTH DISORDERS
See also: Dwarfism; Short Stature

Human Growth Foundation
997 Glen Cove Ave
Glen Head, NY 11545
(800) 451-6434,
(516) 671-4041,
(516) 671-4055 (fax)
✉hgfound@erols.com
http://www.hgfound.org
1,2,3,4,5,6,8,9; Spanish materials

Little People's Research Fund
80 Sister Pierre Dr.
Towson, MD 21204
(800) 232-5773
(410) 494-0055
(410) 494-0062 (fax)
✉lprf@lprf.org
http://www.lprf.org
1,2,8

MAGIC Foundation
1327 N. Harlem Ave.
Oak Park, IL 60302
(800) 362-4423
(708) 383-0808 (fax)
(708) 383-0899
http://www.magicfoundation.org
✉mary@magicfoundation.org
1,2,3,4,5,6,9; Spanish materials, pen pal program for children

GROWTH HORMONE DEFICIENCY
See: Growth Disorders

GROWTH RETARDATION, INTRAUTERINE
See: Growth Disorders

GROWTH RETARDATION-ALOPECIA-PSEUDOANODONTIA-OPTIC ATROPHY
See: Ectodermal Dysplasias

GUERIN-STERN SYNDROME
See: Arthrogryposis Multiplex Congenita

GUILLAIN-BARRÉ SYNDROME
See also: Autoimmune Disorders

Guillain-Barré Syndrome Support Group of Ontario
c/o M.D.A.C
2345 Yonge St., Ste. 901
Toronto, ON CAN M4P 2E5
(800) 567-2873
(519) 747-5777
(519) 747-5987 (fax)
✉info@brenfile.com
1,5,6,8,9

Guillain-Barre Syndrome Foundation International
PO Box 262
Wynewood, PA 19096
(610) 667-0131
(610) 667-7036
http://www.webmast.com/gbs/
✉GBINT@ix.netcom.com

GÜNTHER PORPHYRIA
See: Porphyria

HADDAD SYNDROME
See: Central Hypoventilation Syndrome, Congenital

HAILEY-HAILEY DISEASE
See: Ichthyosis

HAIRY ELBOWS DYSPLASIA
See: Ectodermal Dysplasias

HALLERMAN-STREIFF SYNDROME
See: Craniofacial Disorders; Ectodermal Dysplasias; Short Stature

HALLOPEAU-SIEMENS DISEASE
See: Epidermolysis Bullosa, Dystrophic

HAND-SCHÜLLER-CHRISTIAN SYNDROME
See: Histiocytosis

HAND-SHOULDER SYNDROME
See: ReflexSympathetic Dystrophy Syndrome

HARLEQUIN ICHTHYOSIS
See: Ichthyosis

HAY-WELLS SYNDROME
See: Cleft Palate; Craniofacial Disorders; Deaf-Blind: Ectodermal Dysplasias; Hearing Impairments; Visual Impairments

HAYDEN SYNDROME
See: Ectodermal Dysplasias

HEAD INJURY
See: Brain Injury

HEARING IMPAIRMENTS

Alexander Graham Bell Association for the Deafand hard of hearing
3417 Volta Pl. NW
Washington, DC 20007-2778
(202) 337-5220 (V/TTY)
(202) 337-8314 (fax)
http://www.agbell.org
✉agbell2@aol.com
1,2,3,4,5,6,; Spanish materials, scholarship program

American Society for Deaf Children
1820 Tribute Rd., Ste. A
Sacramento, CA 95815
(800) 942-2732 (V/TTY)
(916) 641-6084
(916) 641-6085 (fax)
http://www.deafchildren.org
✉asdc1@aol.com
1,2,3,4,5,6,7

American Speech, Language, Hearing Association
10801 Rockville Pike
Rockville, MD 20852
(301) 897-5700

Auditory-Verbal International
2121 Eisenhower, Ste. 402
Alexandria, VA 22314
(703) 739-1049
(703) 739-0874 (TTY)
(703) 739-0395 (fax)
✉audiverb@aol.com
http://www.auditory-verbal.org
1,2,3,4,6,7

Better Hearing Institute—U.S. and Canada
5021 Blacklick Rd.
Annandale, VA 22003
(800) 327-9355 (V/TTY)
(703) 642-0580
(703) 750-9302 (fax)
1,2,4

Cochlear Implant Club International
5335 Wisconsin Ave. NW
Suite 440
Washington, DC 20015
(202) 895-2781
(202) 895-2782 (fax)
✉pwms.cici@worldnet.att.net
http://www.cici.org
1,2,3,4,5,6,7,8

Deafness Research Foundation
575 5th Ave, 11th Floor
New York, NY 10017
(800) 535-3323, (Tel/TDD):
(212) 599-0027 (Tel/TDD):
(212) 599-0039 (fax)
✉drf@DRF.org
http://www.drf.org
1,2,4,7,8;

HEAR Now
9745 E. Hampden Ave., Ste. 300
Denver, CO 80231-4923
(800) 648-4327 (V/TTY)
(303) 695-7797 (V/TTY)
(303) 695-7789 (fax)
http://www.leisurelan.com~hearnow/
✉jostetter@aol.com
1,2,7; accepts tax-deductible donations of used hearing aids

KEY TO SERVICES

1 Periodical/newsletter
2 Informational materials
3 Networking/matching
4 Referrals to local resources
5 Local chapters
6 National conferences
7 National advocacy efforts
8 Fund research
9 Maintain research registry

National Resources for Specific Disabilities

John Tracy Clinic for Preschool Deaf Children
806 W. Adams Blvd.
Los Angeles, CA 90007
(800) 522-4582 (V/TTY)
(213) 748-5481
(213) 747-2924 (TTY)
(213) 749-1651 (fax)
http://www.jogntracyclinic.org
✉jtclinic@aol.com
2,3,4; free correspondence course for preschoolers, Spanish materials

Lead Line
House Ear Institute
2100 W. Third St., 5th Flr.
Los Angeles, CA 90057
(800) 352-8888 (V/TTY)
(800) 287-4763 (V/TTY, CA only)
(213) 483-8789 (fax)
http://www.hei.org
✉blincoln@hei.org
2,3,4

National Association of the Deaf
814 Thayer Ave.
Silver Spring, MD 20910-4500
(301) 587-1788
(301) 587-1789 (TTY)
(301) 587-1791 (fax)
http://www.nad.com
✉NADHQ@juno.com
1,2,4,5,6,7; youth program includes Jr NAD clubs and Youth Leadership Camp

(SEE) Center for the Advancement of Deaf Children
PO Box 1181
Los Alamitos, CA 90720
(562) 430-1467 (voice/TTY)
(562) 795-6614 (fax)
✉seectr@aol.com
http://www.seecenter.org
2,4

SHHH: Self Help for Hard of Hearing People
7910 Woodmont Ave., Ste. 1200
Bethesda, MD 20814
(301) 657-2248
(301) 657-2249 (TTY)
(301) 913-9413 (fax)
✉National@shhh.org
http://www.shhh.org
1,2,4,6,8

Telecommunications for the Deaf, Inc.
8630 Fenton St., Ste. 604
Silver Spring, MD 20910-3803
(301) 589-3786
(301) 589-3006 (TTY)
(301) 589-3797 (fax)
1,2,4,6,7

The Canadian Hearing Society
271 Spadina Rd.
Toronto, ON CAN M5R 2V3
(416) 964-9595
(416) 964-0023 (TTY)
(416) 928-2525 (fax)
http://www.chs.ca
✉info@chs.ca
1,2,4,5,6,7; French/Italian/Portuguese/Chinese materials

The Learning to Listen Foundation
Phillips House
North York General Hospital
10 Buchan Ct.
Toronto, ON CAN M2J IV2
(416) 491-4648
1,2,3,4,7

National Cued Speech Association (NCSA)
23970 Hermatage Road
Cleaveland, Ohio 44122-4008
(216) 360-0359
✉cuedspdisc@aol.com
http://www.cuedspeech.org
1,2,3,4,5,6,7

HEART DISORDERS

American Heart Association
7272 Greenville Ave
Dallas, TX 75231-4596
(800) 242-8721
(214) 706-1176
(214) 706-2139 (fax)
http://www.amhrt.org/
✉inquire@amhrt,org
2,3,4,5,6,7,8,9; Spanish materials

CHASER: Congenital Heart Anomalies—Support, Education, & Resources, Inc.
2112 N. Wilkins Rd.
Swanton, OH 43558
(419) 825-5575
(419) 825-2880 (fax)
http://www.csun.edu/~hfmth006/chaser and
http://www.csun.edu/~hfmth006 chaser/chaser-news/html
✉chaser@compuserve.com
✉myer106w@cclc.gov
1,2,3,4,7,9

Children's Heart Association for Support and Education
c/o Cardiac Clinic
Hosp for Sick Children
555 University Ave.
Toronto, ON CAN M5G 1X8
(416) 813-5848
(416) 813-5582
1,2,3,4,8,9

H.E.A.R.T.S. Connection Famiy Resource Center
3101 N. Sillect Ave. Ste. 115
Bakersfield, CA 93308
(661) 328-9055 Ext. 282
(661) 328-9940 (fax)

HEMIDYSPLASIA, UNILATERAL

See: Ichthyosis

HEMIFACIAL MICROSOMIA

See: Goldenhar Syndrome

HEMIHYPERTROPHY

See: Beckwith-Wiedeman Syndrome

HEMIPLEGIA, ALTERNATING

See also: Epilepsy; Seizure Disorders

International Foundation for Alternating Hemiplegia of Childhood
239 Nevada St.
Redwood City, CA 06460
(650) 365-5798
✉laegan@aol.com
1,2,3,8,9

HEMISHPERECTOMY

See: Rasmussen Syndrome

HEMOLYTIC ANEMIA

See: Cooley Anemia

HEMOLYTIC-UREMIC SYNDROME

See: Kidney Disorders

HEMOPHAGOCYTIC LYMPHOHISTIOCYTOSIS

See: Histiocytosis

HEMOPHAGOCYTIC RETICULOSIS

See: Histiocytosis

HEMOPHILIA

National Hemophilia Foundation
116 W.32nd St. 11th Fl.
New York, NY 10001-3212
(800) 424-2634
(212) 328-3700
(212) 328-3777 (fax)
http://www.hemophilia.org
✉info@hemophilia.org
1,2,3,4,5,6,7,8; Spanish materials.

World Federation of Hemophilia
1310 Green Ave., Ste. 500
Montreal, PQ CAN H3Z 2B2
(514) 933-7944
(514) 933-8916 (fax)
http://www.wfh.org
✉wsh@wfh.org
1,2,4,6,8; worldwide referrals, guide for travelers

HEMORRHAGIC NODULAR PURPURA

See: Fabry Disease

HEPATIC DUCTULAR HYPOPLASIA, SYNDROMATIC

See: Alagille Syndrome

HEPATOPHOSPHORYLASE DEFICIENCY GLYCOGENOSIS

See: Glycogen Storage Diseases; Muscular Dystrophy

HEREDITARY KIDNEY DISEASES

See: Kidney Diseases, Hereditary

HEREDITARY LEPTOCYTOSIS

See: Cooley Anemia

HERMANSKY-PUDLAK SYNDROME

See also: Albinism & Hypopigmentation; Visual Impairments

Hermansky-Pudlak Syndrome Network Inc.
1 South Rd.
Oyster Bay, NY 11771
(800) 789-9477
(516) 922-3440
(516) 922-4022 (fax)
http://www.medhelp.org/web/hspn.htm
✉hpsnet@worldnet.att.net
1,2,3,6,8,9;Includes help for families struggling with Chediak Higashi syndrome

HERMAPHRODITISM

See also: Genitalia, Ambiguous

Intersex Society of North America
PO Box 3070
Ann Arbor, MI 48106-3070
(734) 994-7369
(734) 994-7379 (fax)
✉info@isna.org
http://www.isna.org
1,2,3,6

HERNIA, DIAPHRAGMATIC

CHERUBS
PO Box 1150
Creedmoor, NC 27522
(919) 693-8158
http://www.gloryroad.net/~cherubs
✉Cherubs@gloryroad
1,2,3,4,7,9

HERS DISEASE

See: Glycogen Storage Diseases; Muscular Dystrophy

HIRSCHSPRUNG DISEASE

See: Intestinal Pseudo-Obstruction Syndrome

HISTIOCYTOSIS

See also: Growth Disorders; Liver Disorders; Lung Diseases; Pituitary Tumors

Histiocytosis Association of America
302 N. Broadway
Pitman, NJ 08071
(800) 548-2758 (US and Canada)
(856) 589-6606
(856) 589-6614 (fax)
http://www.histio.org
✉hisiocyte@aol.com
1,2,3,4,7,8; Spanish materials

Histiocytosis Association of Canada
2316 Glastonbury Rd.
Burlington, ON CAN L7P 3Y3
(905) 335-2172
✉aprile.duda@sympatico.ca
1,2,3,4,6,8

HIV

See: AIDS

HODGKIN DISEASE

See: Leukemia

HOLOPROSENCEPHALY

See also: Brain Stem Malformations; Chromosomal Abnormalities; Craniofacial Disorders

The Carter Centers for Brain Research in Holoprosencephaly and Related Malformations
Texas Scottish Rite Hospital for Children, Dept. of Neurology
2222 Welborn St.
Dallas, TX 75219
(800) 421-1121
(214) 559-8411
(214) 559-7835 (fax)
✉nclegg@tsrh.org
✉hpe@tsrh.org
1,2,3,4,8,9

HOSPITALITY HOUSING

Children's Hospital International
2202 Mt. Vernon Ave., Ste. 3C
Alexandria, VA 22301
(800) 2-4-CHILD
(703) 684-0330
(703) 684-0226 (fax)
http://www.chionline.org
✉chiorg@aol.com

National Association of Hospital Hospitality Houses
4915 Auburn Ave., Ste. 303
Bethesda, MD 20814
(800) 542-9730
(301) 961-5264
(301)961-3094
http://www.visit_usa.com/hhh
✉nahhhcom@aoi.com

HUMAN IMMUNODEFICIENCY VIRUS

See: AIDS

HUNTER SYNDROME

See: Mucopolysaccharidosis; Tay-Sachs Disease

HURLER SYNDROME

See: Mucopolysaccharidosis; Tay-Sachs Disease

HURLER/SCHEIE SYNDROME

See: Mucopolysaccharidosis; Tay-Sachs Disease

HUTCHINSON-GILFORD SYNDROME

See: Progeria

HUTCHINSON-WEBER-PEUTZ SYNDROME

See: Peutz-Jeghers Syndrome; Polyposis

HYDROCEPHALUS

Guardians of Hydrocephalus Research Foundation
2618 Ave. Z
Brooklyn, NY 11235
(800) 458-8655
(718) 743-4473
(718) 743-1171 (fax)
✉ghrf26189@aol.com
1,2,3; Spanish materials

Hydrocephalus Association
870 Market St., Ste. 705
San Francisco, CA 94102
(888) 598-3789,
(415) 732-7040 (voice),
(415) 732-7044 (fax)
http://www.hydroassoc.org
✉hydroassoc@aol.com
1,2,3,6,7,8,9; Spanish materials

Hydrocephalus Support Group, Inc.
PO Box 4236
Chesterfield, MO 63006-4236
(314) 532-8228
(314) 995-4108 (fax)
✉hydro@inlink.com
1,2,3,4,6,7,9

National Hydrocephalus Foundation
12413 Centralia Rd.
Lakewood, CA 90715-1623
(888)260-1789,
(562)402-3523,
(562)924-6666 (fax)
✉hydrobrat@earthlink.net
http://www.geocities.com/HOTSPRINGS/villa/2300
1,2,3,5,6,8,9; Have videos and cassettes available

HYDROCEPHALUS, OBSTRUCTIVE

See: Dandy-Walker Syndrome

HYPERAMMONEMIA

See: Urea Cycle Disorders

HYPERCALCEMIA SYNDROME, INFANTILE, IDIOPATHIC

See: Williams Syndrome

HYPERCALCEMIA-SUPRAVALVAR AORTIC STENOSIS

See: Williams Syndrome

HYPERCYSTINURIA

See: Cystinuria

HYPERGLYCINEMIA WITH KETOACIDOSIS AND LEUKOPENIA

See: Acidemia, Organic

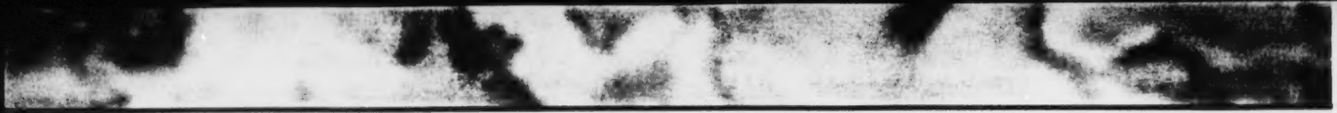
HYPERLEXIA

See: Autism; Language Disorders

Canadian Hyperlexia Association
300 John St.
PO Box 87673
Thornhill,ON CAN L3T 7R3
(905) 886-9163
(905) 886-4624 (fax)
http://www.ican-net/~cha
✉cha@ican.net
1,2,3,5,6,9

KEY TO SERVICES

1 Periodical/newsletter
2 Informational materials
3 Networking/matching
4 Referrals to local resources
5 Local chapters
6 National conferences
7 National advocacy efforts
8 Fund research
9 Maintain research registry



HYPERLIPODEMA
See: Autoimmune Disorders

HYPEROXALURIA
See: Oxalosis & Hyperoxaluria

HYPERTELORISM/ HYPOSPADIUS SYNDROMES
See: Opitz Syndrome

HYPERTHERMIA OF ANESTHESIA
See: Malignant Hyperthermia

HYPERTHYROID MYOPATHY
See: Muscular Dystrophy; Thyroid Disorder

HYPERURICEMIA–CHOREOATHETOSIS–SELF-MUTILATION SYNDROME
See: Lesch-Nyhan Disease

HYPERURICEMIA, HEREDITARY
See: Lesch-Nyhan Disease

HYPODONTIA AND NAIL DYSGENESIS
See: Ectodermal Dysplasias

HYPOERYTHEMIA, PROGRESSIVE
See: Anemia, Aplastic

HYPOGAMMAGLOBULINEMIA
See: Immune Disorders

HYPOMELANOSIS OF ITO
See: Ectodermal Dysplasias; Epilepsy; Incontinentia Pigmenti; Vitiligo

HYPOMYELINATION
See: Myelin Disorders

HYPOPARATHYROIDISM
See also: Thyroid Disorders

Hypoparathyroidism Newsletter
2835 Salmon St.
Idaho Fall, ID 83406
(208) 524-3857
(208) 524-2619 (fax)
✉hpthnews@cyberhighway.net
✉jesand@ida.net
1,3,5,9
http://www.FPI.cyberhighway.net/~hothnews/
✉hpthnews@cyberhighway.net

HYPOPIGMENTATION
See: Albinism & Hypopigmentation; Vitiligo

HYPOPLASIA OF THE CORPUS CALLOSUM
See: Agenesis of the Corpus Callosum

HYPOPLASTIC ANEMIA
See: Anemia, Aplastic

HYPOPLASTIC LEFT HEART SYNDROME
See: Heart Disorders

HYPOSPADIUS/HYPERTELORISM SYNDROMES
See: Opitz Syndrome

HYPOTHYROID MYOPATHY
See: Muscular Dystrophy; Thyroid Disorders

HYPOTHYROIDISM, CONGENITAL
See: Growth Disorders; Thyroid Disorders

HYPOTONIA, BENIGN CONGENITAL
See: Spinal Muscular Atrophy

I-CELL DISEASE
See: Mucopolysaccharidosis; Tay-Sachs Disease

ICHTHYOSIFORM ERYTHRODERMA-DEAFNESS-KERATITS
See: Ectodermal Dysplasias

ICHTHYOSIS

FIRST: Foundation for Ichthyosis and Related Skin Types
PO Box 669
Ardmore, PA 19003
(800) 545-3286
(610) 789-3995
(610) 789-4366 (fax)
✉ichthyosis@aol.com
http://www.libertnet.org/~ichthyos
1,2,3,4,6,7,9; Spanish materials

IDIOPATHIC THROMBOCYTOPENIA PURPURA (ITP)
See: Purpura, Idiopathic Thrombocytopenia (ITP)

IDIOSYNCRATIC PORPHYRIA
See: Porphyria

ILLIOSTOMY
See: Ostomy

ILLNESS, TERMINAL
See also: Bereavement Support

Children's Hospice International
2202 Mt. Vernon Ave., Ste. 3C
Alexandria, VA 22301
(800) 2-4-CHILD (242-4453)
(703) 684-0330
(703) 684-0226 (fax)
✉chiorg@aol.com
http://www.chionline.org
1,2,4,6,7

IMMUNE DEFICIENCY
See: Immune Disorders

IMMUNE DISORDERS
See also: Autoimmune Disorders

Immune Deficiency Foundation
25 W. Chesapeake Ave., Ste. 206
Towson, MD 21204
(800) 296-4433
(410) 321-6647
(410) 321-9165 (fax)
http://www.primaryimmune.org
✉idf@clark.net
1,2,4,5,6,7,8,9; Spanish materials

IMPERFORATE ANUS
See: Anorectal Malformations

INCLUSION BODY MYOSTISIS
See: Immune Disorders

INCONTINENCE

National Association For Continence
PO Box 8310
Spartanburg, SC 29305
(800) 252-3337
(864) 579-7900
(864) 579-7902 (fax)
http://www.nafc.org
✉sbrewer@nafc.org
1,2,7; Spanish materials

Simon Foundation for Continence
PO Box 815
Wilmette, IL 60091
(800) 237-4666
(847) 864-3913
(847) 864-9758 (fax)
http://www.simonfoundation.com
1,2,4,5,6,7; French and Spanish material

INCONTINENTIA PIGMENTI
See also: Ectodermal Dysplasias

National Incontinentia Pigmenti Foundation
30 E. 72th St., 16th Fl.
New York, NY 10021
(212) 452-1231
(212) 452-1406 (fax)
http://www.medhelp.org/www/nipf.html
✉nipf@pipeline.com
1,2,3,4,5,6,9; Informational Materials are provided in eleven different languages, including English, Spanish, French, Italian, Russian, Portuguese, Chinese, Japanese, and others

INCONTINENTIA PIGMENTI ACHROMIANS
See: Ectodermal Dysplasias; Epilepsy; Incontinentia Pigmenti

INDIA RUBBER SKIN
See: Ehlers-Danlos Syndrome

INFANTILE FACIO-SCAPULO-HUMERAL MUSCULAR DYSTROPHY
See: Facio-Scapulo-Humeral Muscular Dystrophy

INFANTILE HYPERCALCEMIA SYNDROME, IDIOPATHIC
See: Williams Syndrome

INFANTILE SPASMS
See: Epilepsy

INTESTINAL NEURONAL DYSPLASIA
See: Intestinal Pseudo-Obstruction Syndrome

INTESTINAL POLYPOSIS
See: Peutz-Jeghers Syndrome; Polyposis

INTESTINAL POLYPOSIS-CUTANEOUS PIGMENTATION SYNDROME
See: Peutz-Jeghers Syndrome; Polyposi

INTESTINAL PSEUDO-OBSTRUCTION SYNDROME

ASAP: American Society of Adults with Pseudo-Obstruction
Young Adults Network
19 Carroll Rd.
Woburn, MA 01801-6161
(781) 935-9776
(781) 933-4151 (fax)
✉asapgi@sprynet.com
1,2,3,4,7,8,9

American Pseudo-Obstruction & Hirschsprung's Disease Society
158 Pleasant St.
North Andover, MA 01845
(978) 685-4477
(978) 685-4488 (fax)
✉aphs@tiac.net
1,2,3,4,6,8,9

INTRAHEPATIC BILE DUCT PAUCITY
See: Alagille Syndrome

INTRAUTERINE GROWTH RETARDATION
See: Growth Disorders

ISOVALERIC ACIDEMIA (IVA)
See: Acidemia, Organic

ISOVALERYL-COA CARBOXYLASE DEFICIENCY
See: Acidemia, Organic

JANSKY-BIELSCHOWSKY DISEASE
See: Batten Disease; Tay-Sachs Disease

JEGHERS SYNDROME
See: Peutz-Jeghers Syndrome; Polyposis

JERVELL & LANGE-NIELSEN SYNDROME
See: Hearing Impairments; Long Q-T Syndrome

JEUNE SYNDROME
See: Growth Disorders

JOHANSON-BLIZZARD SYNDROME
See: Craniofacial Disorders; Ectodermal Dysplasias; Growth Disorders; Hearing Impairments; Short Stature

JORGENSON SYNDROME
See: Ectodermal Dysplasias

JOUBERT SYNDROME
See also: Apnea, Sleep

Joubert Syndrome Foundation
12348 Summer Meadow Rd.
Rock, MI 49880-9552
(906) 359-4707
(906) 359-4707 (fax)
http://www.joubertsyndrome.com
✉joubert@match.org
1,2,3,4,5,6,8,9

JUVENILE GOUT-CHOREOATHETOSIS-MENTAL RETARDATION SYNDROME
See: Lesch-Nyhan Disease

KALLMAN SYNDROME
See: Cleft Palate; Growth Disorders; Hearing Impairments; Kidney Disorders

KAST SYNDROME
See: Cancer; Ollier Disease

KEARNS-SAYRE SYNDROME
See: Heart Disorders; Mitochondrial Disorders; Retinitis Pigmentosa; Visual Impairments

KERATITIS FOLLICULARIS SPINULOSA DECALVANS
See: Ectodermal Dysplasias; Ichthyosis

KERATITIS-ICHTHYOSIS-DEAFNESS (KID) SYNDROME
See: Ectodermal Dysplasias; Ichthyosis; Hearing Impairments

KETOACIDURIA
See: Maple Syrup Urine Disease

KETOTIC HYPERGLYCINEMIA
See: Acidemia, Organic

KID SYNDROME
See: Ectodermal Dysplasias; Ichthyosis; Hearing Impairments

KIDNEY DISEASES, HEREDITARY
See also: Cystinosis; Kidney Disorders, Hereditary; Oxalosis & Hyperoxaluria

Hereditary Nephritis Foundation
PO Box 57294
Murray, UT 84157-0294
(801) 262-1465
1,3,4

KIDNEY DISORDERS
See also: Cystinosis; Kidney Diseases, Hereditary; Oxalosis & Hyperoxaluria

American Association of Kidney Patients
100 S. Ashley Dr., Ste. 280
Tampa, FL 33602
(800) 749-2257
(813) 223-7099
(813) 223-0001 (fax)
✉aakpnat@aol.com
http://www.aakp.org
1,2,4,6,7,8

American Kidney Fund
6110 Executive Blvd., Ste. 1010
Rockville, MD 20852
(800) 638-8299
(301) 881-0898 (fax)
(301) 881-0898
http://www.arbon.com/kidney
✉helpline@akfinc.org
1,2,6,8; Spanish materials, financial assistance for treatment-related expenses

Canadian Pediatric Kidney Disease Research Center
401 Smith Rd.
Ottowa, ON CAN K1H 8L1
(613) 737-4098
(613) 738-4800 (fax)
http://www.cpkdrc.org
2,4

Kidney Foundation of Canada
300-5165 Sherbrooke St. W.
Montreal, PQ CAN H4A IT6
(514) 369-4806
(514) 369-2472 (fax)
✉comm-mktg@kidney.ca
2,3,4,5,8; French/Chinese/Punjabi materials

National Kidney Foundation
30 E. 33rd St., 11th Fl.
New York, NY 10016
(800) 622-9010
(212) 889-2210
(212) 779-0068 (fax)
http://www.kidney.org
1,2,4,5,6,7,8

Polycystic Kidney Research Foundation
4901 Main St., Ste. 200
Kansas City, MO 64112-2634
(800) 753-2873
(816) 931-2600
(816) 931-8655 (fax)
http://www.pkdcure.org
✉pkdcure@pkfoundation.org
1,2,5,6,8; Spanish/French/German/Italian/Japanese materials

KIDNEY STONES
See: Cystinuria

KINKY HAIR DISEASE
See: Menkes Disease

KIRGHIZIAN DERMATOOSTEOLYSIS
See: Ectodermal Dysplasias

KLINEFELTER SYNDROME

49 XXXXY Syndrome Association
10001 NE 74th St.
Vancouver, WA 98662-3801
(360) 892-7547
✉kimbj@juno.com
1,3

Klinefelter's Syndrome Association, Inc.
PO Box 119
Roseville, CA 95661-0119
(916) 773-2999
http://www.genetic.org
✉ks47xxy@ix.netcom.com
1,2,3,4,6,7,9; Spanish materials

Klinefelter's Syndrome Association of America
N5879 30th Rd.
Pine River, WI 54965
(920) 987-5782
1,2,3,5

KEY TO SERVICES

1 Periodical/newsletter
2 Informational materials
3 Networking/matching
4 Referrals to local resources
5 Local chapters
6 National conferences
7 National advocacy efforts
8 Fund research
9 Maintain research registry

National Resources for Specific Disabilities

KLIPPEL-TRENAUNAY SYNDROME
See also: Nevi, Giant Congenital; Sturge-Weber Syndrome; Vascular Malformations

Klippel-Trenaunay Support Group
c/o Judy Vessey
5404 Dundee Rd.
Edina, MN 55424
(612) 925-2596
(612) 333-8685 (fax)
http://www.k-t.org
✉jvessey@usawest.net
1,2,3,4,6,9

KLIPPEL-TRENAUNAY-WEBER SYNDROME
See: Klippel-Trenaunay Syndrome

KRABBE DISEASE
See: Leukodystrophy, Tay-Sachs Disease

KUFS DISEASE
See: Batten Disease; Tay-Sachs Disease

KUGELBERG-WELANDER DISEASE
See: Spinal Muscular Atrophy

KUSSMAUL-LANDRY PARAYLSIS
See: Guillain-Barré Syndrome

KYPHOSIS
See: Scoliosis

LACTATE DEHYDROGENASE DEFICIENCY
See: Muscular Dystrophy

LACTIC ACIDOSIS
See also: Glutaric Aciduria, Type I; Leigh's Disease; Metabolic Disorders

Lactic Acidosis Support Group
1620 Mable Ave.
Denver, CO 80229
(303) 287-4953
2,3,4,9

LAMBERT-EATON SYNDROME
See: Muscular Dystrophy

LANDOUZY-DEJERINE MUSCULAR DYSTROPHY
See: Facio-Scapulo-Humeral Muscular Dystrophy

LANDRY ASCENDING PARAYLSIS
See: Guillain-Barré Syndrome

LANGER-GIEDION SYNDROME
See: Ectodermal Dysplasias; Exostoses, Multiple Hereditary

LANGERHANS CELL HISTIOCYTOSIS
See: Histiocytosis; Language Disorders

LATEX ALLERGY
Latex Allergy Information Service
176 Roosevelt Ave.
Torrington, CT 06790
(860) 482-6869
(860) 482-2294 (fax)
http://www.latexallergyhelp.com
✉76500.1452@compuserve.com
1,2,4,6

LAURENCE-MOON SYNDROME
See: Laurence-Moon-Bardet-Biedl Syndrome

LAURENCE-MOON-BARDET-BIEDL SYNDROME (LMBBS)
See also: Kidney Disorders; Retinitis Pigmentosa

Laurence-Moon-Bardet-Biedl Syndrome Network
18 Strawberry Hill
Windsor, CT 06095
(203) 688-7880
1,2,8

LE JEUNE SYNDROME
See: Cri Du Chat Syndrome

LEARNING DISABILITIES
See also: Attention Deficit Disorder; Dyslexia

Learning Disabilities Association of America
4156 Library Rd.
Pittsburgh, PA 15234
(412) 341-1515
(412) 341-8077
(412) 344-0224 (fax)
✉ldanatl@usaor.org
http://www.ldanatl.org
1,2,4,5,7; Spanish Materials

Learning Disabilities Association of Canada
323 Chapel St, Ste 200
Ottawa, ON CAN K1N 7Z2
(613) 238-5721,
(613) 235-5391 (fax)
✉ldactaac@fox.nstn.ca
http://www.educ.queensu.ca/~ida
1,2,4,5,6,7; French materials

Learning Disabilities Association of New York
27 West 20th St., Ste 303
New York, NY 10011
(212) 645-6730
(212) 924-8896 (fax)

National Center for Learning Disabilities
381 Park Ave S, Ste 3401
New York, NY 10016
(212) 545-7510,
(212) 545-9665 (fax),
(888)575-7373 (inform)
http://www.ncld.org
1,2,4,7

Parents of Gifted/LD Students
2420 Eccleston St.
Silver Spring, MD 20902-4925
(301) 986-1422,
(301) 681-4884 (fax)
✉jilmeyers@aol.com
http://www.geocities.com/athens/1105/gtld.htm
1,2,3,4,5

Resource for Children with Special Needs , Inc
200 Park Ave. S., Ste. 816
New York, NY 10003
(212)677-4650,
(212)254-4040 (fax)
✉resourcesnyc@prodigy.net\
2,4

LEIGH'S DISEASE
See also: Lactic Acidosis; Mitochondrial Disorders

National Leigh's Disease Foundation
608 E. Waldron St., PO Box 2222
Corinth, MS 38834
(800) 819-2551
(601) 286-2551 (fax)
1,2,3,4,7,8,9

LENZ-PASSARGE DYSPLASIA
See: Ectodermal Dysplasias

LEPTOCYTOSIS, HEREDITARY
See: Cooley Anemia

LEPTOMENINGEAL ANGIOMATOSIS
See: Sturge-Weber Syndrome

LESCH-NYHAN DISEASE
International Lesch-Nyhan Disease Association
11042 Ferndale St.
Philadelphia, PA 19116
(215) 677-4206
2,3

International Lesch-Nyhan Disease Registry
Mathenyl School and Hospital
nstitute of Applied Research
PO Box 339
Peapack, NJ 07977
(908) 234-0618
(908) 234-0963
✉info@matheny.org
http://www.matheny.org
2,3,9

Lesch-Nyhan Registry
Dept of Psychiatry
New York Univ., School of Medicine
550 First Ave.
New York, NY 10016
(212) 263-6458
(212) 629-9523 (fax)
✉andersnl@is2.nyu.edu

LETTERER-SIWE DISEASE
See: Histiocytosis

LEUKEMIA
See also: Bone Marrow Transplant; Cancer

Leukemia Research Fund of Canada
Attn: Chris Thomas
1110 Finch Ave. W., Ste. 220
Toronto, ON CAN M3J 2T2
(800) 268-2144 (Canada only)
(416) 661-9541
(416) 661-7799 (fax)
1,2,4,6

Leukemia Society of America
600 Third Ave., 4th Fl.
New York, NY 10016
(800) 955-4572
(212) 573-8484
(212) 450-8844
(212) 856-9686 (fax)
http://www.leukemia.org
1,2,3,4,5,7,8; Spanish materials

LEUKODYSTROPHY
See also: Myelin Disorders, Tay-Sachs Disease

United Leukodystrophy Foundation
2304 Highland Dr.
Sycamore, IL 60178
(800) 728-5483
(815) 895-3211
(815) 895-2432 (fax)
✉ulf@ceet.niu.edu
http://www.ulf.org
1,2,3,6,9; Spanish/French materials

LEUKODYSTROPHY, METACHROMATIC
See: Leukodystrophy, Tay-Sachs Disease

LIMB DISORDERS
See also: Amputation

Superkids: A Newsletter for Families and Friends of Children with Limb Differences
60 Clyde St.
Newton, MA 02460-2250
http://www.superkids.org
1,3

LIMB-GIRDLE MUSCULAR DYSTROPHY
See: Muscular Dystrophy

LIMIT DEXTRINOSIS
See: Glycogen Storage Diseases; Muscular Dystrophy

LIPID HISTIOCYTOSIS
See: Niemann-Pick, Type C Disease

LIPIDOSIS, CEREBROSIDE
See: Gaucher Disease

LIPOFUSCINOSES, NEURONAL CEROID
See: Batten Disease

LIPOID HYPERPLASIA, CONGENITAL
See: Adrenal Disorders

LIPOMYELOMENINGOCELE
Lipomyelomeningocele Family Support Network
321 Hopewell St.
Birdsboro, PA 19508
(610)582-5937
http://www.home.ptd.net/~ifsn
✉gmcafee@ptd.net

LISSENCEPHALY
See also: Epilepsy

Lissencephaly Network
716 Autumn Ridge Ln.
Fort Wayne, IN 46804
(219) 432-4310 (voice/fax)
http://www.lissencephaly.org
✉lta1@is2.nyu.edu
1,2,3,4,9

The Lissencephally Network, Inc.—Canada Division
1549 Regent St.
Regina, SK CAN S4N 1S1
(219) 432-4310
http://www.lissencephaly.org
1,2,3,4,6,8,9; toy-lending library

LIVER DISEASE AND TRANSPLANT (PEDIATRICS)
See also: Liver Disorders

Children's Liver Alliance (formerly the Biliary Atresia & Liver Transplant Network BALT)
3835 Richmond Ave., Box 190
Staten Island, NY 10312-3828
(718) 987-6200 (voice/fax)
http://www.livertx.org
✉Livers4Kids@earthlink.net
1,2,3,4,5,6,7,9; Spanish materials

LIVER DISORDERS
American Liver Foundation
75 Maiden Ln.
Ste. 603
New York, NY 10038-4810
(800) 223-0179,
(800) GO-LIVER,
(888)4-HEP-ABC,
(212) 668-1000,
(212) 668-2000 (fax)
✉webmail@liverfoundation.org
http://www.liverfoundation.org
1,2,4,5,7,8,9; Spanish materials

Canadian Liver Foundation
365 Bloor St. E, Ste. 200
Toronto, ON CAN M4W 3L4
(800) 563-5483 (Canada only),
(416) 964-1953,
(416) 964-0024 (fax)
✉clf@liver.ca
http://www.liver.ca
2,5,6,8; French materials

United Liver Association
3021 Airport Ave
Santa Monica, CA 90064-2987
(310) 313-0707,
(310) 575-5595(fax)
1,2,6,8

LIVER PHOSPHORYLASE DEFICIENCY
See: Glycogen Storage Diseases; Muscular Dystrophy

LOBSTEIN DISEASE, TYPE I
See: Osteogenesis Imperfecta

LONG QT SYNDROME
See also: Heart Disorders

International Long QT Syndrome Registry
PO Box 653
University of Rochester Medical Ctr.
Rochester, NY 14642-8653
(716) 275-5391
(716) 473-2751 (fax)
4,9

Sudden Arrhythmia Death Syndromes (SADS) Foundation
508 E. South Temple, Ste. 20
Salt Lake City, UT 84102
(800) 786-7723
(801) 531-0945 (fax)
http://www.sads.org
✉sads@aros.net
1,2,3,4,5,7,8,9; Spanish materials

LORDOSIS
See: Scoliosis

LOWE SYNDROME
See also: Arthritis; Cystinuria, Glaucoma; Growth Disorders; Kidney Disorders; Metabolic Disorders; Visual Impairments

Lowe Syndrome Association
222 Lincoln St.
W. Lafayette, IN 47906
(765)743-3634
http://www.medhelp.org/lowesyndrome
✉lsa@medhelp.org
1,2,3,4,7,9

LOWE-BICKEL SYNDROME
See: Lowe Syndrome

LOWE-TERRY-MACHLACHLAN SYNDROME
See: Lowe Syndrome

LUNG DISEASES
American Lung Association
1740 Broadway, 14th Fl.
New York, NY 10019
(800) LUNG-USA
(212) 315-8700
(212) 265-5642 (fax)
(212) 315-8872 (fax)
http://www.lung.usa.org
✉info@lungusa.org
2,4,5,6,7,8; Spanish materials

Canadian Lung Association
Attn: Deirdre Freiheit
1900 City Park Dr., Ste. 508
Gloucester, ON CAN K1J 1A3
(613) 747-6776
(613) 747-7430 (fax)
http://www.lung.ca
✉info@lung.ca
2,4,5,6,7

LUPUS ERYTHEMATOSUS
Lupus Foundation of America
1300 Piccard Dr. Ste. 200
Rockville, MD 20850
(800) 588-0121
(888) 38 lupus (385-8787)
(800) 558-0231 (Spanish)
(301) 670-9292,
(301) 670-9486 (fax)
✉info@lupus.org
http://www.lupus.org
1,2,4,5,6,7,8; Spanish materials

SLE Foundation
140 Madison Ave, Ste. 205
New York, NY 10016
(212) 685-4118,
(212) 545-1843 (fax)
✉lupus@lupus.ny
http://www.lupus.org/lupus
1,2,3,4,5,6,7,8; Spanish materials

American Lupus Society
260 Maple Ct, Ste. 123
Ventura, CA 93003
(800) 331-1802 (info line),
(805) 339-0443,
(805) 339-0467 (fax)
1,2,4,5,8

Lupus Canada
PO Box 64034
5512 4th NW
Calgary, AB CAN T2K 6J1
(800) 661-1468,
(403) 274-5599 (phone & fax)
✉lupuscan@cadvision.com
http://www.lupuscanada.org
2,4,5,6,7,8; French materials

LYME DISEASE

American Lyme Disease Foundation, Inc.
Mill Pond Offices.
293 Rt. 100
Somers, NY 10589
(914) 277-6970
(914) 277-6974 (fax)
http://www.aldf.com
✉inquire@aldf.com
1,2,4,6,8

Lyme Disease Foundation
1 Financial Plaza, Gold Bldg., 18th Fl.
Hartford, CT 06103-2610
(800) 886-5953 (info line)
(860) 525-2000
(860) 525-8425 (voice/fax)
http://www.lyme.org
✉lymefnd@aol.com
1,2,4,6,7; Spanish materials; May of 2000, in London

Lyme Disease Resource Center
PO Box 1423
Santa Rosa, CA 95482
(707) 468-8460
✉pcm@pacific.net
1,2,4,6,7

LYMPHANGIOMA

See: Vascular Malformations

LYMPHANGIOMA, CAVERNOUS

See: Lymphatic Malformations

LYMPHATIC MALFORMATIONS

See also: Vascular Malformations

CALM: Children Anguished with Lymphatic Malformations
16 River Bend Rd.
Montgomery, IL 60538
(708) 906-9028
1,2,3,4,9

LYMPHEDEMA

National Lymphedema Network
2211 Post St., Ste. 404.
San Francisco, CA 94115
(800) 541-3259
(415) 921-1306
✉inln@lymphnet.org
http://www.lymphnet.org
1,2,6,7,9

LYMPHOHISTIOCYTOSIS, FAMILIAL ERYTHROPHAGOCYTIC

See: Histiocytosis

LYMPHOHISTIOCYTOSIS, HEMOPHAGOCYTIC

See: Histiocytosis

LYMPHOHISTIOCYTOSIS, MALIGNANT

See: Cancer; Histiocytosis

LYMPHOMA

See: Leukemia

MACULAR DISEASES

See also: Retinitis Pigmentosa; Usher Syndrome; Visual Impairments

Association for Macular Diseases
210 E. 64th St.
New York, NY 10021
(212) 605-3719
(212) 605-3795 (fax)
http://www.macula@macula.org
✉macula@macula.org
1,2,4

Macular Degeneration Foundation
PO Box 9752
San Jose, CA 95157
(888) 633-3937
(408) 260-1335
(408) 260-1336
http://www.eyesight.org
✉eyesight@eyesight.org
1,2,4,9

Stargardt Macular Dystrophy and Other Juvenile Macular Dystrophies Self Help Network
c/o Macular Degeration International
6700 N. Oracle Rd, Ste. 505
Tucson, AZ 85704
(800) 393-7634,
(520) 797-2525,
(520) 797-8018 (fax)
✉info@maculardegeneration.org
http://www.maculardegeneration.org

MACULAR DYSTROPHIES, JUVENILE

See: Macular Diseases

MAFFUCCI SYNDROME

See: Cancer; Ollier Disease

MALE SEX CHROMOSOME DISORDERS

See Klinefelter Syndrome

MALIGNANT HYPERTHERMIA

Malignant Hyperthermia Association
200 Elizabeth St.
CCRW, Rm. 2-834
Toronto, ON CAN M5G 2C4
(416) 340-3238
(416) 340-4960 (fax)
http://www.mhassn.com
✉mha@mhassn.com
1,2,8

Malignant Hyperthermia Association of the United States
39 East State St.
PO Box 1069
Sherburne, NY 13460
(800) 986-4287,
(607) 674-7901,
(800) 674-7910 (fax)
✉mhaus@norwich.net
http://www.mhaus.org
1,2,9; Spanish/Italian materials

North American Malignant Hyperthermia Registry of the Hyperthermia Association of the United States (MHAUS)
Dept of Anesthesia,
Penn State University
PO Box 850
Hershey, PA 17033
(717) 531-6936,
(717) 531-6221 (fax)
✉mhaus@norwich.net
http://www.mhaus.org
9; provides physicians with summaries of consenting, registered patients' anesthesia histories

MANDIBULOFACIAL DYSOSTOSIS

See: Nager & Miller Syndromes; Treacher Collins Syndrome

MANNOSIDOSIS

See: Tay-Sachs Disease

MAPLE SYRUP URINE DISEASE

See also: Acidemia, Organic; Metabolic Disorders

Maple Syrup Urine Disease Family Support Group
5720 Buckfield Ct.
Fort Wayne, IN 46804
(219) 436-0137
1,2,3,6,9; parent-professional network

MARDEN-WALKER SYNDROME

See Cleft Palate; Connective Tissue Disorders; Growth Disorders

MARFAN SYNDROME

See also:Connective Tissue Disorders; Heart Disorders; Scoliosis

Canadian Marfan Association
Centre Plaza Postal Outlet
128 Queen St., S.
PO Box 42257
Mississauga, ON L5M 4Z0
(905) 826-3223
(905) 826-2125
✉info@marfan.ca
http://www.marfan.ca
1,2,3,4,5,6,7,8,9

National Marfan Foundation
382 Main St.
Port Washington, NY 11050-3121
(800) 8MARFAN [862-7326]
(516) 883-8712
(516) 883-8040 (fax)
http://www.marfan.org
✉staff@marfan.org
1,2,3,4,5,6,7,8

MARKER X SYSNDROME

See: Fragile X Syndrome

MARTEAUX-LAMY SYNDROME

See: Mucopolysaccharidosis: Tay-Sachs Disease

MARSHALL SYNDROME, TYPE I

See: Ectodermal Dysplasia

MARTIN-BELL SYNDROME

See: Fragile X Syndrome

MAST CELL DISEASE, SYSTEMIC

Mastocytosis Society
433 E. 300 S.
Spanish Fork, UT 84660-2147
(801) 798-2032
(801) 798-2032
✉cybermom@uswest.net
http://www.mastocytosis.com
1,2,3,4,5,6

MCARDLE DISEASE

See: Glycogen Storage Diseases; Muscular Dystrophy

MCCUNE-ALBRIGHT SYNDROME

See also: Growth Disorders

MAGIC Foundation
McCune-Albright Syndrome Division
1327 N. Harlem Ave.
Oak Park, IL 60302
(800) 362-4423
(708) 383-0808 (fax)
(708) 383-0899
http://www.magicfoundation.org
✉mary@magicfoundation.org
1,2,3,4,5,6,9; Spanish materials, pen pal program for children

MEDITERRANEAN ANEMIA

See: Cooley Anemia

MEDIUM-CHAIN ACYL-COA DEHYDROGENASE DEFICIENCY (MCAD)

See: Fatty Oxidation Disorder

MEDULLOBLASTOMA, HEREDITARY

See: Brain Tumors

MEERKEREN-EHLERS-DANLOS SYNDROME

See: Ehlers-Danlos Syndrome

MEIGE DISEASE

See: Lymphedema

MELANOLEUCODERMA ECTODERMAL DYSPLASIAS

See: Peutz-Jeghers Syndrome; Polyposis

MELAS SYNDROME

See: Growth Disorders, Lactic Acidosis, Mitochondrial Disorders

MELNICK NEEDLES SYNDROME

See: Growth Disorders

MEN SYNDROME I

See: Multiple Endocrine Neoplasia I

MENIERE'S SYNDROME

See: Balance Disorders & Dizziness

MENINGEAL CAPILLARY ANGIOMATOSIS

See: Sturge-Weber Syndrome

MENKES DISEASE

See also: Liver Disorders; Metabolic Disorders

Corporation for Menkes Disease
5720 Buckfield Ct.
Fort Wayne, IN 46804
(219) 436-0137
1,2,3,6,9; Parent-professional network

MENTAL ILLNESS

See also: Mental Retardation/Mental Illness

Canadian Mental Health Association
2160 Yonge St.
Toronto, ON CAN M4S 2Z3
(416) 484-7750
(416) 484-4617 (fax)
✉cmhanat@interlog.com
http://www.icomm.ca/cmhacan
1,2,4,5,6,7; French materials

Federation of Families for Children's Mental Health
1021 Prince St.
Alexandria, VA 22314-2971
(703) 684-7710
(703) 836-1040 (fax)
✉ffcmh@crosslink.net
http://www.ffcmh.org
1,2,3,4,5,6,7; Spanish materials,

National Alliance for the Mentally Ill
200 N Glebe Rd., Ste. 10150
Arlington, VA 22203-3754
(703) 524-7600
(703) 524-9094 (fax)
✉NAMIOFFC@aol.com
http://www.nami.org
1,2,3,4,5,6,7,8

National Mental Health Association
1021 Prince St.
Alexandria, VA 22314-2971
(800) 969-6642 (info line)
(703) 684-5968
✉namiofc@aol.com
http://www.cais.com/vikings/nami/index.html
1,2,3,4,5,6,9

National Mental Health Services Knowledge Exchange Network (KEN)
11426-28
Rockville Pike, Ste. 405
Rockville, MD 20852
✉ken@mentalhealth.org
http://www.mentalhealth.org
(800) 789-2647
(301) 984-8796 (fax)

MENTAL RETARDATION

See also: Mental Illness; Mental Retardation/ Mental Illness

The Arc
1010 Wayne Ave., Ste. 650
Silver Spring, MD 20910
(800) 433-5255
(301) 565-3842
(301) 565-3843 (fax)
✉thearc@metronet.com
http://www.TheArc.org/welcome.html
1,2,4,5,6,7,8; Spanish materials.

Bethpage
2245 Midway Rd., Ste. 300
Carrolton, TX 75006
(972) 866-9989
(972) 991-0834
✉psanchez@bethpage.org
1,2,5,6

Bethphage
The Lind Center, Ste. A.
4980 S 118th St.
Omaha, NE 68137-2220
(402) 896-3884
(402) 896-1511 (fax)
✉mburke@bethphage.org
http://www.bethphage.org

KEY TO SERVICES

1 Periodical/newsletter
2 Informational materials
3 Networking/matching
4 Referrals to local resources
5 Local chapters
6 National conferences
7 National advocacy efforts
8 Fund research
9 Maintain research registry

National Resources for Specific Disabilities

Canadian Association for Community Living & The Roeher Institute
4700 Keele St.
Kinsman Bldg, York University
North York, ON CAN M3J 1P3
(416) 661-9611
(416) 661-2023 (TTY)
(416) 661-5701 (fax)
✉info@roeher.ca
✉info@cacl.ca.roeher.ca
http://www.cacl.ca
1,2,3,4,5,6,7,8,9; French materials

People First International
PO Box 12642
Salem, OR 97309
(503) 362-0336
(503) 585-0287 (fax)
✉heathd@open.org
http://www.open.org/people1/peple1/:htm
1,2,4,6,8; leadership/self-advocacy training

Voice of the Retarded
5005 Newport Dr., Ste. 108
Rolling Meadows, IL 60008
(847) 253-6020
(847) 253-6054 (fax)
✉vor@compuserve.com
1,2,3,4,7

MENTAL RETARDATION/MENTAL ILLNESS

See also: Mental Illness; Mental Retardation

(AAMR) American Association on Mental Resources
44 N Capitol St., Ste. 846
Washington, DC 20001
(800) 424-3688
(202) 387-1968
(202)387-2193 (fax)
✉aamr@access.digex.net
http://www.aamr.org
1,2,4,5,6

Developmental Disabilities Nurses Association (DDNA)
228 Grimes St., Ste. 246
Eugene, OR 97402
(800) 888-6733
(541) 485-7372 (fax)
✉ddnahq@aol.com
http://www.ddna.org
1,2,4,5,6,8

National Association of the Dually Diagnosed (NADD)
132 Fair St.
Kingston, NY 12401
(800) 331-5362
(914) 331-4336
(914) 331-4569 (fax)
✉thenadd@aol.com
http://www.thenadd.org
1,2,3,4,5,6,7

MERRF SYNDROME

See: Myoclonus; Mitochondrial Disorders

METABOLIC DISORDERS

See also: Acidemia, Organic; Galactosemia; Lactic Acidosis; Maple Syrup Urine Disease; Niemann-Pick Disease; Phenylketonuria (PKU)

Association for Neurometabolic Disorders
5223 Brookfield Ln.
Sylvania, OH 43560-1809
(419) 885-1497
1,3,6

Canadian Society for Metabolic Disease
3738 Sunset St.
Barnaby, BC CAN V5g 1T2
(604) 435-0085 (voice/fax)
1,2,3,4,6,8,9

Metabolic Information Network
PO Box 670847
Dallas, TX 75367-0847
(800) 945-2188 (USA/Canada)
(214) 696-2188
(800) 955-3258 (fax, USA/Canada)
(214) 696-3258 (fax)
✉mizesg@ix.netcom.com *1*

The Research Trust for Metabolic Diseases in Children (RTMDC)
Golden Gates Lodge
Weston Road, Crewe
Cheshire, England CW25XN
00441270 250221
00441270 250244 (fax)
1,2,3,4,5,6,7,8,9; English, French, German, Spanish materials

The World Life Foundation
PO Box 571
Bedford, TX 76095-0571
(800) 289-5433
Offers air transport for client and one parent to facility for metabolic disorders treatment.

METACHROMATIC LEUKODYSTROPHY

See: Leukodystrophy, Tay-Sachs Disease

METAPHYSEAL DYSOSTOSIS, TYPE B IV

See: Shwachman Syndrome

METHYLMALONIC ACIDEMIA

See: Acidemia, Organic

MICROCEPHALY

Microcephaly Network
362 Jean Talon
St. Vanier, ON CAN K1L 6T9
(613) 742-5936
✉amanda@inetdirect.com
http://www.microcephaly.org

MICROPHTHALMIA

See: Anophthalmia; Visual Impairments

MICROSOMIA, HEMIFACIAL

See: Craniofacial Disorders; Goldenhar Syndrome

MICROTIA

See also: Craniofacial Disorders

Microtia-Atresia Support Group
c/o Jack Gross
330 7th Ave., #1203
New York, NY 10001
(212) 947-0770
(212) 714-1224 (fax)
✉GrossinsCo@aol.com
3

MIKAELIAN SYNDROME

See: Ectodermal Dysplasias

MILLER SYNDROME

See: Nager & Miller Syndromes

MILLER-DIEKER SYNDROME

See: Lissencephaly

MILLER-FISCHER SYNDROME

See: Guillain-Barré Syndrome

MILROY DISEASE

See: Lymphatic Malformations; Lymphedema

MITOCHONDRIAL DISORDERS

United Mitochondrial Disease Foundation (UMDF)
COX Foundation for all Mitochondrial Diseases
PO Box 1151
Monroeville, PA 15146-1151
(412) 793-8077
(412) 793-6466 (fax)
http://biochemgen.ucsd.edu/umdf/
1,2,3,5,6,7,8,9

MITOCHONDRIAL MYOPATHY

See: Mitochondrial Disorders; Muscular Dystrophy

MOEBIUS SYNDROME

See also: Craniofacial Disorders; Limb Disorders

Moebius Syndrome Support Group
38883 FoxHolm Dr.
Palmdale, CA 93551
(805) 267-2570 (voice/fax)
✉lorit@netport.com
http://www.wincom.net/moebius/
1,2,3,6,8,9

MONOSOMY X

See: Turner Syndrome

MORQUIO SYNDROME

See: Mucopolysaccharidosis; Tay-Sachs Disease

MORVAN DISEASE

See: Syringomyelia

MOTOR-SENSORY NEUROPATHY, HEREDITARY

See: Charcot-Marie-Tooth Disease

MOYAMOYA DISEASE

See: Stroke; Vascular Malformations

Families with Moyamoya Network
c/o Dawn Gruettner
4900 McGowan St., SE
Cedar Rapids, IA 52403
(800) 261-6892
2,3

MUCOLIPIDOSES

See: Mucopolysaccharidosis; Mucolipidosis Type IV; Tay-Sachs Disease

MUCOLIPIDOSIS TYPE IV

See also: Mucopolysaccharidosis; Tay-Sachs Disease; Visual Impairments

ML4 Foundation
719 East 17th St.
Brooklyn, NY 11230
(718) 434-5067
(718) 859-7371 (fax)
✉ml4@aol.com
http://www.ml4.org
1,2,3,4,5,7,8,9

MUCOPOLYSACCHARIDOSIS

See also: Metabolic Disorders; Tay-Sachs Disease

National Mucopolysaccharidosis (MPS) Society
102 Aspen Dr.
Downingtown, PA 19335
(610) 942-0100
✉presmps@aol.com
http://www.mpssociety.org
1,2,3,4,5,6,8,9; Spanish materials

MUCOSULFATIDOSIS

See: Hearing Impairments; Ichthyosis; Leukodystrophy; Tay-Sachs Disease

MULTIPLE CARBOXYLASE DEFICIENCY

See:Metabolic Disorders

ENCHONDROSES

See: Ollier Disease

MULTIPLE ENDOCRINE NEOPLASIA I

See also: Adrenal Disorders; Diabetes Mellitus; Thyroid Disorders

Multiple Endocrine Neoplasia I
c/o Mrs. Cathy McMillan-Fitch
Box 100
Meota, SK CAN S0M 1X0
(306) 892-2080 (voice/fax)
✉hockey_freak99@hotmail.com
3,9

MULTIPLE SCLEROSIS

Multiple Sclerosis Society of Canada
250 Bloor St E, Ste. 1000
Toronto, ON CAN M4W 3P9
(800) 361-2985 (Canada only)
(416) 922-6065
(416) 922-7238 (fax)
✉info@mssoc.ca
http://www.mssoc.ca
1,2,4,6,7,8,9

National Multiple Sclerosis Society
733 3rd Ave., 6th Fl.
New York, NY 10017-3288
(800) 344-4867
(212) 986-3240
(212) 986-7981 (fax)
✉nat@nmss.org
http://www.nmss.org
1,2,4,5,8; Spanish materials

MULTIPLE SULFATASE DEFICIENCY

See: Hearing Impairments; Ichthyosis; Leukodystrophy; Tay-Sachs Disease

MUSCLE PHOSPHOFRUCTOKINASE DEFICIENCY

See: Glycogen Storage Diseases; Muscular Dystrophy

MUSCLE PHOSPHORYLASE DEFICIENCY

See: Glycogen Storage Diseases; Muscular Dystrophy

MUSCULAR ATROPHY, PERONEAL

See: Charcot-Marie-Tooth Disease

MUSCULAR DYSTROPHY

See also: Facio-Scapulo-Humeral Muscular Dystrophy; Ventilator Use

Duchenne Parent Project
125 Marymount Ct.
Middletown, OH 45042-3755
(800) 714-KIDS
(513) 424-7452
(513) 425-9907
✉patfurlong@aol.com
http://www.parentdmd.org

MUSCULAR DYSTROPHY, DEJERINE-LANDOUZY

See also: Facio-Scapulo-Humeral Muscular Dystrophy; Ventilator Use

Muscular Dystrophy Associatio
3300 E. Sunrise Dr.
Tucson, AZ 85718-3208
(800) 572-1717
(520) 529-2000
(520) 529-5300 (fax)
✉mda@mdausa.org
http://www.mdausa.org
1,2,3,4,5,8; Spanish materials, local clinics, provides assistanc with wheelchair and leg brace purchases and repairs; summer camps; support groups.

Muscular Dystrophy Associatio of Canada
2345 Yonge St., Ste. 901
Toronto, ON CAN M4P 2E5
(800) 567-2873 (Canada only)
(416) 488-0030
(416) 488-7523 (voice/fax)
✉ragbar@mdac.ca
http://www.mdac.ca
1,2,3,4,5,6,8,9; French materials

Muscular Dystrophy Family Foundation
615 N. Alabama St., Ste. 330
Indianapolis, IN 46204
(800) 544-1213
(317) 632-8255
(317) 632-1722 (fax)

Society for Muscular Dystrophy Information International
PO Box 479
Bridgewater, NS CAN B4V 2X6
(902) 685-3961
(902) 685-3962 (fax)
✉smdi@aura.com.com
http://www.auracom.com/~smidi/index.html
1

MUSCULAR DYSTROPHY, FACIO-SCAPULO-HUMERAL

See: Facio-Scapulo-Humeral Muscular Dystrophy

MYASTHENIA GRAVIS

Myasthenia Gravis Association
25 Caravan Dr.
North York, ON CAN M3B 1M9
(416) 444-8357
1,2,4,5,8,9

Myasthenia Gravis Foundation of America
123 W, Madison, Ste. 800
Chicago, IL 60602
(800) 541-5454
(312) 853-0523 (fax)
Ωmyastheniagravis@msn.com
http://www.myasthenia.org
1,2,4,5,6,7,8,9; Spanish material.

MYASTHENIC SYNDROME OF LAMBERT-EATON

See: Charcot-Marie-Tooth Disease

MYELIN DISORDERS

See also: Leukodystrophy, Myelin, Insufficient

The Canadian Myelin Research Initiative
c/o Julie and Wayne Simmons
4330 Spinningdale Ct.
Mississauga, ON CAN L5M 3J8
(905) 567-8843
(905) 567-9189 (fax)
✉myelin@interlog.com
2,6,7,8,9

The Myelin Messenger
7320 N. Stable Ln.
Prescott, AZ 86305
(520) 776-7556
1,3

The Myelin Project
1747 Pennsylvania Ave. NW.
Ste. 950
Washington, DC 20006
(202) 452-8994
(202) 785-9578 (fax)
✉myelin@erols.com
http://www.myelin.org/
1,2,8;Italian/French/German/Danish/Spanish materials.

MYELODYSPLASIA
See: Anemia, Aplastic

MYELOMA
See also: Cancer; Leukemia

International Myeloma Foundation
2129 Stanley Hills Dr.
Los Angeles, CA 90046
(800) 452-2873
(213) 654-3023
(213) 656-1182 (fax)
✉theimf@aol.com
http://www.comed.com/imf/imf.html
1,2,3,4,6,7,8

MYELOMA, MULTIPLE
See: Myeloma

MYELOSYRINGOSIS
See: Syringomyelia

MYOADENYLATE DEAMINASE DEFICIENCY
See: Muscular Dystrophy

MYOCLONUS
See also: Epilepsy; Opsoclonus-Myoclonus Syndrome

Moving Forward
2934 Glenmore Ave.
Kettering, OH 45409
(513) 293-0409
✉editormdp@aol.com
http://www.acor.org/diseases/hematology/mpd
2

MYODENYLATE DEAMINASE DEFICIENCY
See: Muscular Dystrophy

MYOPATHIES, CONGENITAL
See: Myotubular Myopathy, X-Linked

MYOPATHY, CENTRONUCLEAR
See: Myotubular Myopathy, X-Linked; Muscular Dystrophy

MYOPATHY, HYPERTHYROID
See: Muscular Dystrophy; Thyroid Disorders

MYOPATHY, HYPOTHYROID
See: Muscular Dystrophy; Thyroid Disorders

MYOPHOSPHORYLASE DEFICIENCY
See: Glycogen Storage Diseases

MYOSITIS
See also: Autoimmune Disorders

National Myositis Association
7720B El Camino Real, Ste. 367
Rancho La Costa, CA 92009
(800) 230-0441
(619) 436-2185
1,2,3,4,5,9

MYOSITIS OSSIFICANS
See: Fibrodysplasis Ossificans Progressiva

MYOTONIA, CONGENITA
See: Muscular Dystrophy

MYOTUBULAR MYOPATHY, X-LINKED
See also: Muscular Dystrophy

X-Linked Myotubular Myopathy Resource Group
2602 Quaker Dr.
Texas City, TX 77590
(409) 945-8569
✉gscoggin@aol.com
http://www.mtmrg.org
1,2,3,9

MYXEDEMA
See: Thyroid Disorders

N-ACETYL GLUTAMATE SYNTHETASE (NAGS) DEFICIENCY
See: Urea Cycle Disorders

NAEFELI-FRANCESCHETTI-JADASSOHN DYSPLASIA
See: Ectodermal Dysplasias

NAEGELI-FRANCESCHETTI-JADASSOHN SYNDROME
See: Incontinentia Pigmenti

NAGER & MILLER SYNDROMES
See also: Craniofacial Disorders; Hearing Impairments; Limb Disorders

Foundation for Nager and Miller Syndromes (FNMS)
1827 Grove St. #2
Glenview, IL 60025-2913
(800) 507-3667
(847) 724-6449 (fax)
✉fnms@interaccess.com
http://www.nagerormillersynd.com
1,2,3,4,5,6,8,9

NASAL ENCEPHALOCELE
See: Craniofacial Disorders

NEMALINE MYOPATHY
See: Muscular Dystrophy

NEPHRITIS
See: Kidney Diseases, Hereditary, Fetal Alcohol Syndrome

NEUROFIBROMATOSIS
See also: Acoustic Neuroma; Hearing Impairments; Visual Impairments

National Neurofibromatosis Foundation
95 Pine St., 16th Fl
New York, NY 10005
(212) 344-6633
(212) 747-0004 (fax)
(800) 323-7938 Voice
✉nnff@nf.org
http://www.nf.org

Neurofibromatosis Foundation
95 Pine St., 16th Fl.
New York, NY 10005
(800) 323-7938 (V/TTY)
(212) 344-6633
(212) 747-0004 (fax)
✉nnff@aol.com
http://www.nf.org
1,2,4,5,8

Neurofibromatosis, Inc
8855 Annapolis, Ste. 110
Lanham, MD 20706-2924
(800) 942-6825
(301) 577-8984
(301) 577-0016 (fax)
✉nfinc1@aol.com
http://www.nfinc.org
1,2,3,4,5,7,8

Neurofibromatosis Society of Ontario
923 Annes St.
Whitby, ON CAN L1N 5K7
(905) 430-6141 (voice/fax)
1,2,4,6,8

NEUROLOGICAL DISORDERS

Association for Comprehensive Neurotherapy
1128 Royal Palm Beach Blvd.,
283
Royal Palm Beach, FL 33411
(561) 798-0472,
(561) 798-9820 (fax)
✉acn@latitudes.org
http://www..latitudes.org

Making Headway Foundation, Inc
115 King St.
Chappaqua, NY 10514-3460
(914) 238-8384,
(914) 238-1693 (fax)
1,2,4,8

NEUROMETABOLIC DISORDERS
See: Metabolic Disorders

NEURONAL CEROID LIPOFUSCINOSES
See: Batten Disease

NEUROPATHY, HEREDITARY, SENSORY MOTOR
See: Charcot-Marie-Tooth Disease

NEUROPATHY, PERIPHERAL
See: Charcot-Marie-Tooth Disease

NEUTROPENIA

Neutropenia Support Assoc., Inc.
PO Box 243
905 Corydon Ave.
Winnipeg, MB CAN R3M 3S7
(800) 663-8876; (204) 489-8454
✉stevensl@neutropenia.ca
http://www.neutropenia.ca
1,2,3,4,5,6,7,Promotes chapter development and involement with the Neutropenia SCN International Regisry French materials

Neutropenia SCN International Registry
Puget Sound Plaza
1325 4th Ave., Ste. 620
Seattle, WA 98101-2509
(800) 726-4463
(206) 543-9749
(206) 543-3668 (fax)
✉registry@u.washington.edu
http://www.scnir.medicine.washington.edu/
1,2

NEUTROPENIA-PANCREATIC INSUFFICIENCY
See: Shwachman Syndrome

NEVI, GIANT CONGENITAL
See also: Craniofacial Disorders;; Ichthyosis; Klippel-Trenaunay Syndrome; Sturge-Weber Syndrome; Vascular Malformations

Nevus Network
PO Box 1981
Woodbridge, VA 22193
(703) 492-0253,
✉nevusnet@bigfoot.com
http://www.nevusnetwork.org
1,2,3,9; French/Spanish materials

NEVILLE DISEASE
See: Niemann-Pick Disease

NEVO SYNDROME
See: Sotos Syndrome

NIEMANN-PICK TYPE C DISEASE
See also: Ataxia; Metabolic Disorders; Tay-Sachs Disease

Ara Parseghian Medical Research Foundation
1760 E River Rd., Ste. 115
Tucson, AZ 85718
(520) 577-5106
(520) 577-5212 (fax)
✉victory@aparseghian.org
http://www.parseghian.org
1,2,3,4,7

NONKETOTIC HYPERGLYCINEMIA
See: Acidemia, Organic

NONNE-MILROY-MEIGE SYNDROME
See: Lymphatic Malformations; Lymphedema

NOONAN SYNDROME
See also: Cardio-Facio-Cutaneous Syndrome; Growth Disorders; Heart Disorders; Malignant Hyperthermia; Williams Syndrome

(TNSSG) Noonan Syndrome Support Group, Inc.
PO Box 145
Upperco, MD 21155
(888) 686-2224
(410) 374-5245
✉wandar@bellatlantic.net
http://www.noonansyndrome.org

NORMAN-ROBERTS SYNDROME
See: Lissencephaly

NORRIE DISEASE
See also: Hearing Impairments; Visual Impairments

Norrie Disease Foundation Developmental Neurogenetics Unit
Mass General Hospital
CNY #6217
149 13 St.
Charlestown, MA 02129
(617) 726-5718
(617) 724-9620 (fax)
✉sims@helix.mgh.harvard.edu
http://www.neuro-.mgh.harvard.edu
2,3,4

NUTRITION

The Oley Foundation
214 Hun Memorial A-23
Albany Medical Center
Albany, NY 12208
(800) 776-OLEY
(578) 262-5079
(518) 262-5528
✉joan_bishop@ccgateway.amc.
http://www.wizvax.net/oleyfdn

NYHAN SYNDROME
See: Lesch-Nyhan Syndrome

OAV SYNDROME
See: Goldenhar Syndrome

OBSESSIVE COMPULSIVE DISORDER

OC Foundation
PO Box 70
Milford, CT 06460
(203) 878-5669
(203) 874-2826 (fax)
✉info@ocfoundation.org
http://www.ocfoundation.org
1,2,3,4,5,6,7,8

OBSTRUCTIVE HYDROCEPHALUS
See: Dandy-Walker Syndrome

OCULO-AURICULO-VERTEBRAL SPECTUM
See: Goldenhar Syndrome

OCULOCEREBRORENAL SYNDROME
See: Lowe Syndrome

OCULODENTODIGITAL SYNDROME; TYPE I & II
See: Ectodermal Dysplasias

OCULOOSTEOCUTANEOUS SYNDROME
See: Ectodermal Dysplasias

ODONTOONYCHODERMAL DYSPLASIA
See: Ectodermal Dysplasias

ODONTOONYCHOHYPOHIDROTIC DYSPLASIA
See: Ectodermal Dysplasias

ODONTOTRICHODYSPLASIA WITH NEUTROPENIA
See: Ectodermal Dysplasias; Neutropenia

ODONTOTRICHOMELIC SYNDROME
See: Ectodermal Dysplasias

OLDFIELD SYNDROME
See: Peutz-Jeghers Syndrome; Polyposis

KEY TO SERVICES
1 Periodical/newsletter
2 Informational materials
3 Networking/matching
4 Referrals to local resources
5 Local chapters
6 National conferences
7 National advocacy efforts
8 Fund research
9 Maintain research registry

OLIGOPHRENIA-MICROPHTHALMOS
See: Norrie Disease

OLIGOSACCHARIDOSES
See: Tay-Sachs Disease

OLLIER DISEASE
See also: Growth Disorders

Ollier's/Maffuci Self-Help Group
c/o Bonnie Hatch-schmid Founder
c/o Hermann Schmid Secretary
Newletters Offices
1824 Millwood Rd.
Sumter, SC 29150
(803) 775-1757
(803) 469-9749
✉olliers@aol.com
http://www.uhsweb.edu.olliers/olliers.htm
1,3,4,9

ONDINE'S CURSE
See: Central Hypoventilation Syndrome, Congenital

OPITZ FG SYNDROME
See: Opitz Syndrome

OPITZ HYPERTELORISM-HYPOSPADIUS SYNDROME
See: Opitz Syndrome

OPITZ OCULOGENITOLARYNGEAL SYNDROME
See: Opitz Syndrome

OPITZ SYNDROME

Opitz G/BBB Family Network
PO Box 516
Grand Lake, CO 80447
(970) 627-8935 (phone/fax)
✉opitznet@rkymtnhi.com
http://www.rkymtnhi.com/opitz
1,2,3,9

OPITZ-BBBG COMPOUND SYNDROME
See: Opitz Syndrome

OPITZ-FRIAS SYNDROME
See: Opitz Syndrome

OPSOCLONUS-MYOCLONUS SYNDROME
See also: Epilepsy; Myoclonus

Opsoclonus-Myoclonus Parent-Talk Support Network
c/o Connie Quinn
725 North St.
Jim Thorpe, PA 18229
(717) 325-3302
✉clquinn@ptd.net
http://www.geocities:com/hotsprings/spa/2.
3,9

OPTIC NERVE HYPOPLASIA
See: Septo-Optic Dysplasia

ORBITAL HYPERTELORISM
See: Craniofacial Disorders

ORGANIC ACIDEMIA
See: Acidemia, Organic

ORNITHINE TRANSCARBAMYLASE (OTC) DEFICIENCY
See: Urea Cycle Disorders

OROFACIODIGITAL SYNDROME, TYPE I
See: Ectodermal Dysplasias

OSLER-WEBER-RENDU SYNDROME
See: Hemorrhagic Telangiectasis, Hereditary

OSTEITIS FIBROSA DISSEMINATA
See: McCune-Albright Syndrome

OSTEOCHONDROMATOSIS
See: Exostoses, Multiple Hereditary

OSTEOGENESIS IMPERFECTA
See also: Growth Disorders

Canadian Osteogenesis Imperfecta Society
128 Thornhill Crescent
Chatha, ON CAN N7L 4M3
(519) 436-0025
(519) 351-4043 (fax)
✉mkearney@kent.net
1,2,3,6

Osteogenesis Imperfecta Foundation
804 West Diamond Ave., Ste. 210
Gaithersburg, MD 20878
(800) 981-2663
(301) 947-0083
(301) 947-0456 (fax)
✉bonelink@oif.org
http://www.oif.org
1,2,3,4,5,6,7; Support groups; Spanish materials

OSTOMY

United Ostomy Association, Inc.
19722 MacArthur Blvd., Ste. 200
Irvine, CA 92612
(800) 826-0826
(949) 660-8624
(949) 660-9262 (fax)
✉uoa@deltanet.com
http://www.uoa.org
1,2,4,5,6,7; National Confrence in Reno Nevada in July

Ostomy Association of Canada, Inc
PO Box 46057
College Park PO
444 Yonge St
Toronto, ON CAN M5B 2L8
(416) 595-5452
(416) 595-9924 (fax)
✉uoacan@magic.com
http://business.atcon.com/voacanada/
1,2,3,4,5,6,7,9; youth network

OXALOSIS & HYPEROXALURIA
See also: Kidney Disorders

Oxalosis & Hyperoxaluria Foundation
12 Pleasant St..
Maynard, MA 01754
(888)721-2432 PIN#5392
(978)461-0614
✉ohf@ohf.ultranet.com
http://www.ohf.org
2,3,8,9

OXOPROLINURIA
See: Acidemia, Organic

PACHYGYRIA
See: Lissencephaly

PACHYONYCHIA, CONGENITAL
See: Ectodermal Dysplasias

PAGON SYNDROME
See: Hydrocephalus; Lissencephaly

PALLISTER-HALL SYNDROME
See also: Anorectal Malformations; Pituitary Tumors

Pallister-Hall Foundation
RFD Box 3000
Fairground Rd.
Bradford, VT 05033
(802) 222-9683
✉messer@sover.net
2,3,4,9

PALLISTER-KILLIAN SYNDROME
See also: Epilepsy

Pallister-Killian Family Support Network
3700 Wyndale Ct.
Ft Worth, TX 76109
(817) 927-8854
(817) 927-2073 (fax)
3

PALMOPLANTAR HYPERKERATOSIS AND ALOPECIA
See: Ectodermal Dysplasias

PANCREATIC INSUFFICIENCY WITH NEUTROPENIA
See: Shwachman Syndrome

PANCYTOPENIA, CONGENITAL
See: Anemia, Fanconi

PANHYPOPITUITARISM
See: Growth Disorders

PANMYELOPATHY
See: Anemia, Aplastic

PANMYELOPHTHISIS
See: Anemia, Aplastic

PAPILLOMAS
See: Respiratory Papillomatosis, Recurrent

PAPILLON-LEFEVRE SYNDROME
See: Ectodermal Dysplasias

PARALYSIS, PERIODIC
See: Muscular Dystrophy

PARALYTIC POLIO
See: Polio

PARAMYOTONIA CONGENITA
See: Muscular Dystrophy

PARKES-WEBER SYNDROME
See: Klippel-Trenaunay Syndrome

PARRY-ROMBERG SYNDROME
See: Craniofacial Disorders

PATIN SYNDROME
See: Fibrodysplasis Ossificans Progressiva

PDD
See: Autism

PELIZAEUS-MERZBACHER DISEASE
See: Leukodystrophy

PEMPHIGUS, FAMILIAL
See: Ichthyosis

PEPCK DEFICIENCY
See: Lactic Acidosis; Mitochondrial Disorders

PERIPHERAL NEUROPATHY
See: Charcot-Marie-Tooth Disease

PERONEAL MUSCULAR ATROPHY
See: Charcot-Marie-Tooth Disease

PERVASIVE DEVELOPMENTAL DISORDER (PDD)
See: Autism

PEUTZ-JEGHERS SYNDROME
See also: Polyposis

Hereditary Colon Cancer Registry
c/o Jill D. Brensinger
Johns Hopkins Hospital
550 N Broadway, Ste. 108
Baltimore, MD 21205
(410) 614-4038
(410) 614-9544 (fax)
✉hccregistry@jhmi.edu
2,3,4,8,9

PEUTZ-TOURAINE SYNDROME
See: Peutz-Jeghers Syndrome; Polyposis

PFEIFFER SYNDROME
See: Craniofacial Disorders

PHAKOMATOSIS
See: Tuberous Sclerosis

PHENYLKETONURIA (PKU)
See also: Metabolic Disorders

Children's PKU Network
1520 State St., Ste. 111
San Diego, CA 92101
(619) 233-3202
(619) 233-0838 (fax)
✉pkunetwork@aol.com
1,2,3,4,9; Spanish materials

National PKU News
c/o Virginia Schuett
6869 Woodlawn Ave NE, Ste. 116
Seattle, WA 98115-5469
(206) 525-8140
(206) 525-5023 (fax)
✉schuett@pkunews.org
http://www.wolfenet.com/~kronmal
1,2

PHOSPHOENOLPYRUVATE CARBOXYKINASE DEFICIENCY
See: Lactic Acidosis; Mitochondrial Disorders

PHOSPHOFRUCTOKINASE DEFICIENCY
See:Glycogen Storage Diseases; Muscular Dystrophy

PHOSPHOGLYCERATE KINASE DEFICIENCY
See: Muscular Dystrophy

PHOSPHOGLYCERATE MUTASE DEFICIENCY
See: Muscular Dystrophy

PHOSPHORYLASE B KINASE DEFICIENCY
See: Glycogen Storage Diseases; Muscular Dystrophy

PHOSPHORYLASE DEFICIENCY GLYCOGEN STORAGE
See: Diseases; Muscular Dystrophy

PIERRE ROBIN SYNDROME
See: Craniofacial Disorders; Growth Disorders

PIGMENT DISORDERS
See: Albinism & Hypopigmentation; Vitiligo

PILI TORTI AND ENAMEL HYPOPLASIA
See: Ectodermal Dysplasias

PILI TORTI AND ONYCHODYSPLASIA
See: Ectodermal Dysplasias

PITUITARY DISORDERS

Pituitary Tumor Network Association
16350 Ventura Blvd., Ste. 231
Encino,CA 91436
(805) 499-9973
(805)499-1523 (fax)
✉ptna@pituitary.com
http://www.pituitary.com
1,2,3,4,7,9

PITUITARY TUMORS
See also: Pituitary Disorders

Pituitary Tumor Support Network of Canada
61 Markbrook Ln.
Etiboke, ONT CAN M9V 5E7
(416) 749-1997
1,2,3,4,6,8

PITYRIASIS RUBRA PILARIS
See: Ichthyosis

POLIO

Informed Parents Against VAPP (vaccine associated paralytic polio)
PO Box 53212
Washington, DC 20009
(888) 363-8277
(703) 319-8277 (fax)
✉NOVAPP@aol.com
http://www.ipav.org
2,3,7,8,9

International Polio Network
4207 Lindell Blvd, #110
Saint Louis, MO 63108-2915
(314) 534-0475
(314) 534-5070 (fax)
✉gini_intl@msn.com
http://www.post-polio.org
1,2,3,4,5,6,7; Local support groups.

POLYCYSTIC KIDNEY DISEASE
See: Kidney Disorders

POLYENDOCRINE ADENOMATOSIS
See: Multiple Endocrine Neoplasia I

POLYMYOSITIS
See: Muscular Dystrophy; Myositis

POLYNEURITIS, ACUTE IDIOPATHIC
See: Guillain-Barré Syndrome

POLYNEUROPATHY, CHRONIC RELAPSING
See: Guillain-Barré Syndrome

POLYOSTOTIC FIBROUS DYSPLASIA
See: McCune-Albright Syndrome

POLYPOSIS
See also: Cancer; Peutz-Jeghers Syndrome

Familial Gastrointestinal Cancer Registry
Mount Sinai Hospital
600 University Ave., Ste. 1157
Toronto, ON CAN M5G 1X5
(416) 586-8334,
(416) 586-8644((fax)),
✉tburke@mtsinai.on.ca
1,2,3,4,9; French materials

POLYRADICULONEUROPATHY
See: Guillain-Barré Syndrome

POMPE DISEASE
See also: Glycogen Storage Diseases; Muscular Dystrophy; Tay-Sachs Disease

The Children's Pompe Foundation
66 Witherspoon St., Ste. 341
Princeton, NJ 08542
(609) 924-7192
(609) 924-7143 (fax)
http://www.pompe.org
1,2

PORPHYRIA

Metabolic Disorders American Porphyria Foundation
PO Box 22712
Houston, TX 77227
(713) 266-9617
(713) 871-1788
✉porphyrus@juno.com
http://www.enterprise.net/apf
1,2,3,4,7,8,9

Metabolic Disorders Canadian Porphyria Foundation
Box 1206
Neepawa, MB CAN R0J 1H0
(204) 476-2800 (voice/fax)
1,2,3,9; French materials

PORT WINE STAINS
See: Sturge-Weber Sydrome

POSTAXIAL ACROFACIAL DYSOSTOSIS
See: Nager & Miller Syndromes

PRADER-WILLI SYNDROME

Ontario Prader-Willi Syndrome Association
1920 Yonge St. c104
Toronto, ON CAN M4S 3B2
(800) [illegible]63-1123
(416) 481-8657 (voice/fax)
✉prader-willi@sympatico.ca
http://www3.sympatico.ca/prader-willi/
1,2,3,4,5,8,9; French materials

Prader-Willi Foundation
223 Main St.
Port Washington, NY 11050
(800) 253-7993
(516) 944-3173 (fax)
✉foundation@prader-willi.inter.net
http://prader_willi.inter.net
2,3,4,7,8

The Prader-Willi Syndrome Association (USA)
5700 Midnight Pass Rd., Ste 6
Sarasota, FL 34242
(800) 926-4797
(941) 312-0400
(941) 312-0142
✉pwsausa@aol.com
http://www.pwsausa.org
1,2,3,4,5,6,7,8,9 English, Spanish and French materials

PROGERIA

International Progeria Registry
c/o W. Ted Brown, MD, PhD
NY State Inst. for Basic Research in Developmental Disabilities
1050 Forest Hill Rd.
Staten Island, NY 10314
(718) 494-5333
(718) 494-1026 (fax)
✉wtbibr@aol.com
3,9

PROGRESSIVE HYPOERYTHEMIA
See: Anemia, Aplastic

PROGRESSIVE OSSEOUS HETEROPLASIA
See: Connective Tissue Disorders; Fibrodysplasis Ossificans Progressiva

PROPINONYL-COA CARBOXYLASE (PCC)
See: Deficiency Acidemia, Organic

PROPIONIC ACIDEMIA
See: Acidemia, Organic

PROTEUS SYNDROME
See: Neurofibromatosis

PROTOCOPROPORPHYRIA
See: Liver Disorders; Porphyria

PROTOPORPHYRIA
See: Liver Disorders; Porphyria

PRUNE BELLY SYNDROME

Prune Belly Syndrome Network
100 UCLA Medical Plaza Ste. 690
Los Angeles, CA 90095
(310) 825-6865
(310) 794-9962 (fax)
http://www.pedsuro.com
3,4,5,9

PSEUDO-HURLER POLYDYSTROPHY
See: Mucopolysacchandosis; Tay-Sachs Disease

PSEUDOCHOLINESTERASE DEFICIENCY
See: Malignant Hyperthermia

PSEUDOXANTHOMA ELASTICUM (PXE)
See also: Connective Tissue Disorders; Heart Disorders; Macular Diseases; Visual Impairments

National Association for Pseudoxanthoma Elasticum
3500 E. 12th Ave.
Denver, CO 80218-1910
(303) 355-3866
(800) 832-3765
(303)355-3859
✉(at Texas Tech.)
derckd@ttuhsc.edu
✉(at Denver hdqtrs.)
prenape@estreet.com
http://www.napxe.org
1,2,3,4,6,9; newsletter provided on tape; low-vision clinic.

PSORIASIS

Canadian Psoriasis Foundation
1306 Wellington St., Ste 500A
Ottawa, ON CAN K1Y 3B2
(800) 265-0926 (Canada only)
(613) 728-4000
(613) 728-8913 (fax)
1,2,4,5,6,8; French materials

National Psoriasis Foundation
6600 SW 92nd Ave., Ste.300
Portland, OR 97222
(503) 244-7404
(503) 245-0626 (fax)
✉getinfo@npsusa.org
http://www.psoriasis.org
1,2,3,4,6,7,8,9; Spanish materials

PTOSIS
See: Blepharophimosis, Ptosis, Epicanthus Inversus Syndrome (BPES)

PULMONARY VALVULAR STENOSIS
See: Heart Disorders

PURINE METABOLIC DISORDERS

Purine Research Society
5424 Beech Ave.
Bethesda, MD 20814-1730
(301) 530-0354
(301)564-9597 (fax)
✉purine@erols.com
http://www2.dgsys.com/~purine/
1,2,3,5,6,7

PURPURA HEMORRHAGICA
See: Purpura, Idiopathic Thrombocytopenia (ITP)

PURPURA, IDIOPATHIC THROMBOCYTOPENIA (ITP)

ITP Society
Children's Blood Foundation
333 E. 38th St.
New York, NY 10016-2745
(800) 487-7010
(212) 297-4340
(212)297-4336
✉cbf@nyp.org
http:// www.ultranet.com/~itpsoc
1,2,3,7,8,9

PYRIMIDINE METABOLIC DISORDERS
See: Purine Metabolic Disorders

PYROGLUTAMICACIDURIA
See: Acidemia, Organic

PYRROLORPHYRIA
See: Porphyria

PYRUVATE CARBOXYLASE DEFICIENCY
See: Acidemia, Organic; Lactic Acidosis; Leigh Disease

PYRUVATE DEHYDROGENASE DEFICIENCY
See: Acidemia, Organic; Lactic Acidosis; Leigh Disease

PYRUVATE DEHYDROGENASE PHOSPHATASE
See: Lactic Acidosis; Leigh Disease

Q-T PROLONGATION
Long Q-T Syndrome

RAPP-HODGKINS SYNDROME
See: Cleft Palate; Craniofacial Disorders; Deaf-Blind; Ectodermal Dysplasias; Hearing Impairments; Visual Impairments

RASMUSSEN ENCEPHALITIS
See: Rasmussen Syndrome

RASMUSSEN SYNDROME
See: Epilepsy; Seizure Disorders

Rasmussen Syndrome Support Group
c/o Al and Lynn Miller
8235 Lethbridge Rd
Millersville, MD 21108
(410) 987-5221 (voice/fax)
✉rssnlynn@aol.com
http://medhip.netusa.net/
http://www/rasm.htm
1,2,3,5,6,9; Spanish/French/Russian/Greek materials

RECKLINGHAUSEN DISEASE
See: Neurofibromatosis

REFLEX SYMPATHETIC DYSTROPHY SYNDROME

Reflex Sympathetic Dystrophy Syndrome Association of America
116 Haddon Ave, Ste. D
Haddonfield, NJ 08033
(609) 795-8845 (voice/fax)
http://www.rsds.org
1,2,3,4,6,8,9

REFRACTORY ANEMIA
See: Anemia, Aplastic

REFSUM DISEASE
See: Ichthyosis; Leukodystrophy; Tay-Sachs Disease

RENAL DISORDERS
See: Kidney Disorders

RENDU-OSLER-WEBER SYNDROME
See: Hemorrhagic Telangiectasis, Hereditary

RESPIRATORY PAPILLOMATOSIS, RECURRENT

Recurrent Respiratory Papillomatosis Foundation
PO Box 6643
Lawrenceville, NJ 08648-0643
(609) 530-1443
(609) 258-3943 (fax)
✉mstern@pucc.princeton.edu
http://members.aol.com/rrpf/rrpf.html
1,2,3,4,7,8,9

RETINITIS PIGMENTOSA
See also: Macular Diseases; Stargardt Disease; Usher Syndrome; Visual Impairments

Retinitis Pigmentosa International
23241 Ventura Blvd.
Woodland Hills, CA 91364
(800) 344-4877
(818) 992-0500
(818) 992-3265 (fax)
✉RPINT@pacbell.net
http://www.rpinternational.org
1,2,4,7,8,9; Spanish materials

RETINITIS PIGMENTOSA
See also: Macular Diseases; Usher Syndrome; Visual Impairments

RP Research Foundation Fighting Blindness
c/o Sharon Cole or Margot Alward
36 Toronto St, Ste 910
Toronto, ON CAN M5C 2CS
(800) 461-3331 (Canada only)
(416) 360-4200
(416) 360-0060 (fax)
1,2,3,5,7,8; French materials

RETINITIS PIGMENTOSA
See also: Macular Diseases; Usher Syndrome; Visual Impairments

The Foundation Fighting Blindness
Executive Plaza 1, Ste. 800
11350 McCormick Rd.
Hunt Valley, MD 21031
(888) 394-3937
(410) 771-9470 (fax)
http://www.blindness.org
1,2,3,4,5,6,8,9; young adult program, retina donor program.

RETINOBLASTOMA
See: Cancer; Visual Impairments

National Retinoblastoma Parent Group
PO Box 317
Watertown, MA 02471
(800) 562-6265
1,2,3,4,6,9

RETINOCEREBRAL ANGIOMATOSIS
See: Von Hippel-Lindau Syndrome

RETINOPATHY OF PREMATURITY (ROP) DH
See also: Neonatal Illness/Prematurity; Visual Impairments

Prevent Blindness in Premature Babies
PO Box 44792
Madison, WI 53744-4792
2,3,4,9

RETT SYNDROME

International Rett Syndrome Association
9121 Piscataway Rd., Ste. 2B
Clinton, MD 20735
(800) 818-7388
(301) 856-3334
(301) 856-3336 (fax)
✉irsa@rettsyndrome.org
http://www.rettsyndrome.org
1,2,3,4,6,7,8,9; Spanish/French/Russian/German materials.

Ontario Rett Syndrome Association
147 Westdale Rd.
Oakville, ON CAN L6L 4Z7
(905) 844-7673
(905) 884-8730 (fax)
✉rettsont@cgocable.net
http://www.cgocable.net/~rettsont
1,2,3,4,5,7,8,9

REYE SYNDROME
See: Fatty Oxidation Disorder

RILEY-DAY SYNDROME
See: Familial Dysautonomia

RING CHROMOSOME 15
See also: Chromosome Deletions; Craniofacial Disorders; Epilepsy; Heart Disorders; Kidney Disorders; Limb Disorders; Scoliosis

KEY TO SERVICES

1 Periodical/newsletter
2 Informational materials
3 Networking/matching
4 Referrals to local resources
5 Local chapters
6 National conferences
7 National advocacy efforts
8 Fund research
9 Maintain research registry

RING CHROMOSOME 18
See: Chromosome 13 & 18 Disorders; Chromosome 18 Disorders Chromosome Deletions; Craniofacial Disorders; Deaf-Blind; Hearing Impairments; Visual Impairments

RING CHROMOSOME 21
See: Chromosome Deletions

RING CHROMOSOME 22
See: Chromosome Deletions

RING CHROMOSOME 4
See: Chromosome Deletions; Wolf-Hirschhorn Syndrome

RING CHROMOSOME 6
See: Chromosome 6 Disorders

RING CHROMOSOME 9
See: Chromosome Deletions; Craniofacial Disorders

ROBINOW SYNDROME
See also: Craniofacial Disorders; Short Stature

Robinow Syndrome Foundation
c/o Karla M. Kruger
15955 Uplander St. NW
Andover, MN 55304-2501
(612) 434-1152
(612) 778-2331 (fax)
1,2,3

ROBINSON SYNDROME
See: Ectodermal Dysplasias

ROMANO-WARD SYNDROME
See: Long Q-T Syndrome

ROSAI-DORFMAN DISEASE
See: Histiocytosis

ROSSELI-GULIENETTI SYNDROME
See: Ectodermal Dysplasias

ROTHMUND-THOMPSON'S SYNDROME
See: Ectodermal Dysplasias

RSH SYNDROME
See: Smith-Lemli-Opitz Syndrome

RUBINSTEIN SYNDROME
See: Rubinstein-Taybi Syndrome

RUBINSTEIN-TAYBI SYNDROME
See also: Craniofacial Disorders; Heart Disorders

Rubinstein-Taybi Parent Group
c/o Lorrie Baxter
PO Box 146
Smith Center, KS 66967
(785) 697-2984
(785) 697-2985 (fax)
✉lbaxter@ruraltel.net
http://www.tucson.com/rts
1,2,3,9

RUSSELL SYNDROME
See: Russell-Silver Syndrome

RUSSELL-SILVER SYNDROME
See also: Growth Disorders; Short Stature

Russell-Silver Support Group
1327 Harlem Dr.
Oak Park, IL 60302
(800) 3- Magic -3
(313)586-8038
✉slantana@awol.com
http://www.nettap.com/-magic
2,3,4,5,6

SAETHRE-CHOTZEN SYNDROME
See: Craniofacial Disorders

SALAMON SYNDROME
See: Ectodermal Dysplasias

SANDHOFF DISEASE
See: Tay-Sachs Disease

SANFILIPPO SYNDROME
See: Mucopolysaccharidosis; Tay-Sachs Disease

SCHEIE SYNDROME
See: Mucopolysaccharidosis; Tay-Sachs Disease

SCHINZEL-GIEDION SYNDROME
See:"Apnea, Sleep; Deaf-Blind; Ectodermal Dysplasias; Epilepsy; Growth Disorders; Hearing Impairments; Visual Impairments"

SCID
See: Immune Disorders

SCLERODERMA
See also: Arthritis; Autoimmune Disorders

Scleroderma Federation
Peabody Office Bldg.
89 Newbury St.
Panvers, MA 01923
(800) 722-HOPE
(978) 750-4499
(978) 750-9902 (fax)
✉sclerofed@aol.com
http://www.scleroderma.org
1,2,3,4,5,6,7,8,9

Scleroderma Research Foundation
PO Box 200
Columbus, NJ 08022
(800) 637-4005
(609) 723-7400
(609) 723-6700 (fax)
1,2,4

United Scleroderma Foundation, Inc.
89 Newbury St.
Danvors, MA 01923
(800) 722-HOPE (4673)
(978)750-4499
(978)535-6696 (fax)
✉sfinfo@aol.com
http://www.scleroderma.com
1,2,4,5,6,7,8,9.

SCOLIOSIS
National Scoliosis Foundation
5 Cabot Pl.
Stoughton, MA 02072
(800) 673-6922
(781) 341--6333
(781) 341-8333
✉scoliosis@aol.com
http://www.scoliosis.org
1,2,3,4,5,6,7

SECKEL SYNDROME
See: Craniofacial Disorders; Growth Disorders

SEIZURE DISORDERS
See also: Epilepsy

THRESHOLD—Intractable Seizure Disorder Support Group & Newsletter
Lion Head Office Park., Ste 8A
Brick, NJ 08733
✉efsnj@aol.com
http://www.efnj.com
1

SENSORY AND AUTONOMIC NEUROPATHY, HEREDITARY
See: Familial Dysautonomia

SENSORY MOTOR NEUROPATHY, HEREDITARY
See: Charcot-Marie-Tooth Disease

SENSORY NEUROPATHY WITH ANHIDROSIS, CONGENITAL
See: Familial Dysautonomia

SEPTO-OPTIC DYSPLASIA
See also: Pituitary Tumors; Visual Impairments

FOCUS: For Our Children's Unique Sight
2571 Pico Pl.
San Diego, CA 92109
(619) 273-1473 (voice/fax)
✉daphari@adnc.com
http://www.telepath.com/canance/focus/
1,2,3,9

SERUM PROTEASE INHIBITOR DEFICIENCY
See: Alpha-1-Antitrypsin (AAT) Deficiency

SEVERE COMBINED IMMUNODEFICIENCY (SCID)
See: Immune Disorders

SEX CHROMOSOME DISORDERS, FEMALE
See: Turner Syndrome

SEX CHROMOSOME DISORDERS, MALE
See: Klinefelter Syndrome

SHORT STATURE
See also: Dwarfism; Growth Disorders

Little People of America
PO Box 745
Lubbock, TX 79408
(806) 797-8830 (voice/fax; call first)
Engl./Span.
(888)572-2001 (voice/fax; call first)
✉lpadatabase@juno.com
http://www.lpaonline.com
1,2,3,5,6; Spanish materials

LPBC: A Society for Short Stature Awareness
Box 4280
Vancouver, BC CAN V6B 3Z7
(604) 688-4757
✉mmrlpbc@bc.sympatico.ca
1,2,3,4,6

SHPRINTZEN SYNDROME
See: Velo-Cardio-Facial Syndrome

SHWACHMAN SYNDROME
See: Growth Disorders

Shwachman Syndrome Support Services
c/o Joan Mowery
4118 Quincy St.
St. Louis, MO 63116
(314) 352-1821 (phone/fax)
✉jmowery@mo.net
http://www.xmission.com/~4sskids
1,2,3,4,7,9; French/Italian/Dutch materials

SHWACHMAN-DIAMOND SYNDROME
See: Shwachman Syndrome

SHY-DRAGER
Shy-Drager Syndrome Support Group
LVanderbilt University Autonomic Dysfunction Center
Nashville, TN 37232
(800) 505-4999
(615) 343-6499

SIALIDOSIS
See: Mucopolysaccharidosis; Tay-Sachs Disease

SIALOLIPIDOSIS
See: Mucolipidosis Type IV

SICKLE CELL ANEMIA
See: Sickle Cell Disease

SICKLE CELL DISEASE
Sickle Cell Disease Association of America
200 Corporate Pointe, Ste. 495
Culver City, CA 90203-7633
(800) 421-8453
(310) 216-6363
(310) 215-3722 (fax)
1,2,3,4,5,6,8,9; National Confrence, September 8 - 11, in Cleaveland Ohio

Sickle Cell Disease Association of the Piedmont
1102 E Market St.
Greensboro, NC 27401-0964
(800) 733-8297
(336) 274-1507
(336) 275-7984 (fax)
✉scdap@aol.com
http://www.greensboro.com/sickle/
1,2,3,4,7

Sickle Cell Society
6999 Cote Des Neiges, Ste .33
Montreal, PQ CAN H3S 2B8
(514) 735-5109
(514) 735-5100 (fax)
2,3,4,8,9; French materials

SIDS
See: Sudden Infant Death Syndrome (SIDS)

SILVER SYNDROME
See: Russell-Silver Syndrome

SILVER-RUSSELL SYNDROME
See: Russell-Silver Syndrome

SIMPSON-GOLABI-BEHMEL SYNDROME
See: Beckwith-Wiedermann Syndrome

SKELETAL ANOMALIES
See: Ectodermal Dysplasias

SKELETAL DYSPLASIA
See: Dwarfism; Growth Disorders; Short Stature

SLEEP APNEA
See: Apnea, Sleep

SLO SYNDROME
See: Smith-Lemli-Opitz Syndrome

SLY SYNDROME
See: Mucopolysaccharidosis; Tay-Sachs Disease

SMITH-LEMLI-OPITZ SYNDROME
See: Craniofacial Disorders

Smith-Lemli-Opitz Advocacy & Exchange
32 Ivy Ln.
Glen Mills, PA 19342
(610) 361-9663
http://www.members.aol.com/slo97/index.htm
1,2,3,6,9

SMITH-MAGENIS SYNDROME
PRISMS: Parents & Researchers Interested in Smith-Magenis Syndrome
11875 Fawn Ridge Ln.
Reston, VA 20194
(703) 709-0568
acmsmith@nchgr.nih.gov
1,2,3,4,6,9

SOTOS SYNDROME
See also: Growth Disorders

Sotos Syndrome USA Support Association
PMB #235
3 Danada Sq E.
Wheaton, IL 60187
(888) 246-SSSA
(630) 682-8815 (international)
✉sssa@well.com
http://www.well.com/user/sssa/
1,2,3,4,6

SOUQUES-CHARCOT SYNDROME
See: Progeria

SOUTH AFRICAN GENETIC PORPHYRIA
See: Liver Disorders; Porphyria

SPASMODIC DYSPHONIA
See: Dystonia

SPASMODIC TORTICOLLIS
See: Dystonia

SPASMODIC WRYNECK
See: Dystonia

SPASTIC PARAPLEGIA, FAMILIAR
See: Ataxia

SPEECH DISORDERS
See: Aphasia; Apraxia; Stuttering

SPHINGOMYELIN LIPIDOSIS
See: Niemann-Pick Disease

SPIELMEYER-VOGT DISEASE
See: Batten Disease

SPIELMEYER-VOGT-BATTEN SYNDROME
See: Batten Disease

SPINA BIFIDA
See also: Arnold-Chiari Malformation; Hydrocephalus; Incontinence; Latex Allergy

Spina Bifida Association of America
4590 MacArthur Blvd. NW, Ste. 250
Washington, DC 20007-4226
(800) 621-3141
(202) 944-3285
(202) 944-3295 (fax)
✉sbaa@abaa.org
http://www.sbaa.org
1,2,4,5,6,8; Spanish materials, scholarship program

Spina Bifida and Hydrocephalus Association of Canada
220-388 Donald St.
Winnipeg, MB CAN R3B 2J4
(800) 565-9488 (Canada only)
(204) 925-3650
(204) 925-3654 (fax)
✉spinab@mts.net
http://www.sbhac.ca
1,2,4,5,6,7,8; French materials

SPINAL CORD INJURIES

See also: Ventilator Use

Christopher Reeve Paralysis Foundation
500 Morris Ave.
Springfield, NJ 07081
(800) 225-0292
(973) 379-2690
(973) 912-9433 (fax)
✉paralysis@aol.com
http://www.paralysis.org
1,2,7

National Spinal Cord Injury Association
8300 Colesville Rd., Ste. 551
Silver Spring, MD 20910
(800) 962-9629 (hotline only)
(301) 588-6959
(301) 588-9414 (fax)
NSCIA2@aol.com
http://www.trader.com/users/5010/1020/nscia.htm
1,2,3,4,5,8; Spanish materials

National Spinal Cord Injury Hotline
2200 Kernon Dr.
Baltimore, MD 21207
(800) 526-3456
(410) 448-6623 (local)
(410) 488-6627 (fax)
✉scihotline@aol.com
http://www.scihotline.org
2,3,4,5

SPINAL MUSCULAR ATROPHY

See also: Muscular Dystrophy; Ventilator Use

Families of SMA
PO Box 196
Libertyville, IL 60048-0196
(800) 886-1762
(847) 367-7620
(847) 367-7623 (fax)
✉sma@interaccess.com
http://www.fsma.org
1,2,3,4,5,6,7,8,9; Spanish materials

SPINOCEREBELLAR ATAXIA

See: Ataxia; Friedreich Ataxia

SPLENIC ANEMIA, FAMILIAL

See: Gaucher Disease

SPONDYLOEPIPHYSEAL DYSPLASIA CONGENITA

See: Cleft Palate; Growth Disorders; Visual Impairments

SPONDYLOEPIPHYSEAL DYSPLASIA TARDA

See: Growth Disorders

SSPE

See: Subacute Sclerosing Panencephalitis

STAR PROTEIN DEFICIENCY

See: Adrenal Disorders

STEELY HAIR DISEASE

Menkes Disease

STENGEL SYNDROME

See: Batten Disease

STENGEL-BATTEN-MAYOU-SPIELMEYER-VOGT DISEASE

See: Batten Disease

STICKLER SYNDROME

Stickler Involved People (SIP)
15 Angelina Dr.
Augusta, KS 67010
(316) 775-2993
http://www.stickler.org
✉sip@stickler.org
1,2,3,6

STROKE

See also: Aphasia, Acquired

National Stroke Association
96 Inverness Dr. East, Ste 1
Englewood, CO 80112-5112
(800) 787-6537
(303) 649-9299
(303) 649-1328 (fax)
✉info@stroke.org
http://www.stroke.org
1,2,5,6,7,8; Spanish/French materials

STROKE

See also: Heart Disorders

Heart and Stroke Foundation of Canada
222 Queen St. Ste 1402
Ottawa, ON CAN K1P 5V9
(613) 569-4361
(613) 569-3278 (fax)

STURGE-WEBER SYNDROME

See also: Craniofacial Disorders; Epilepsy; Glaucoma; Klippel-Trenaunay Syndrome; Nevi, Giant Congenital; Neurofibramatosis; Tuberous Sclerosis; Vascular Malformations; Von Hippel-Lindau Syndrome

Sturge-Weber Foundation
PO Box 418
Mount Freedom, NJ 07970
(800) 627-5482
(927) 895-4445
(927) 895-4846 (fax)
✉swf@sturge-weber.com
http://www.sturge-weber.com
1,2,3,4,6,7,8,9

Sturge-Weber Foundation (Canada) Inc
1960 Prairie Ave.
Port Coquitlam, BC CAN V3B 1V4
(604) 942-9209
(604) 942-6429 (fax)
✉kmoore@axionet.com
http://www.inforamp.net/~cvs0590
1,2,3,4,6,7,8,9

STUTTERING

National Center for Stuttering
200 East 33rd St.
New York, NY 10016
(800) 221-2483
(212) 683-1372 (fax)
✉executivedirector@stuttering.com
http://www.stuttering.com
2,4,5; Spanish materials

Speak Easy
c/o Mike Hughes
95 Evergreen Ave.
St John, NB CAN E2N 1H4
(506) 696-6799 (voice/fax)
✉info@speakeasycanada.com
http://www.speakeasycanada.com
1,2,4,5,6,8

Stuttering Foundation of America
PO Box 11749
Memphis, TN 38111-0749
(800) 992-9392
(901) 452-7343
(901) 452-3931 (fax)
stuttersfa@aol.com
http://www.stuttersfa.org
1,2,4; Spanish materials

SUBACUTE NECROTIZING ENCEPHALOPATHY

See: Leigh Disease

SUBACUTE SCLEROSING PANENCEPHALITIS

See also: Epilepsy; Visual Impairments

National Subacute Sclerosing Panencephalitis Registry
c/o Paul Dyken, Director
Institute of Research in Childhood Neurodegenerative Disorders
PO Box 70191
Mobile, AL 36610-0191
(334) 478-6424
(334) 476-8277 (fax)
pdyken@awol.com
2,6,9

SUCCINYLCHOLINE SENSITIVITY

See: Malignant Hyperthermia

SUDDEN INFANT DEATH SYNDROME (SIDS)

See also: Bereavement Support

Canadian Foundation for the Study of Infant Deaths
586 Eglinton Ave E., Ste. 308
Toronto, ON CA M4P1P2
(800) 363-7437
(416) 488-3260
(416) 488-3864 (fax)
sidscanada@inforamp.net
http://www.sidscanada.org/sids
1,2,3,4,5,6,8; French/Spanish materials

National Sudden Infant Death Syndrome Resource Center
8201 Greensboro Dr. Ste 600
McLean, VA 22102
(703) 821-8955
(703) 821-2098 (fax)
http://www.ichp.ufl.edu/mch_netlink/sids/sids1.htm
1,2,4; Spanish materials

SUDECK ATROPHY

See: Reflex Sympathetic Dystrophy Syndrome

SULFATIDOSIS, JUVENILE, AUSTIN TYPE

See: Hearing Impairments; Ichthyosis; Leukodystrophy; Tay-Sachs Disease

SURDICARDIAC SYNDROME

See: Hearing Impairments; Long Q-T Syndrome

SWEDISH PORPHYRIA

See: Porphyria

SYNDACTYLIC OXYCEPHALY

See: Apert Syndrome

SYRINGOBULBIA

See: Syringomyelia

SYRINGOMYELIA

See also: Arnold-Chiari Malformation

ASAP: American Syringomyelia Alliance Project
PO Box 1586
300 Green St. Ste. 206
Longview, TX 75606-1586
(800) 272-7282
(903) 236-7079
(903) 757-7456 (fax)
✉102563.3507@compuserve.com
http://www.dataprompt.com/syringo
1,2,3,6,9

SYSTEMIC ELASTORRHEXIS OF TOURAINE

See: Pseudoxanthoma Elasticum (PXE)

SYSTEMIC MAST CELL DISEASE

See: Mast Cell Disease

TANGIER DISEASE

See: Tay-Sachs Disease

TARGET CELL ANEMIA

See: Cooley Anemia

TARUI DISEASE

See: Glycogen Storage Diseases; Muscular Dystrophy

TAY SYNDROME

See: Ichthyosis

TAY-SACHS DISEASE

National Tay-Sachs and Allied Diseases Association
2001 Beacon St., Ste 204
Boston, MA 02135
(800) 90-NTSAD
(617) 277-4463
(617) 277-0134 (fax)
✉ntsad-boston@worldnet.att.net
http://www.ntsad.org
1,2,3,4,5,6,7,8, Russian materials

TEF

See: VACTERL Association

TESCHLER-NICOLA/KILLIAN SYNDROME

See: Pallister-Killian Syndrome

THALASSEMIA MAJOR

See: Cooley Anemia

THROMBOCYTOPENIA ABSENT RADIUS (TAR) SYNDROME

See also: Heart Disorders; Kidney Disorders; Short Stature

Thrombocytopenia Absent Radius Syndrome Association
212 Sherwood Dr
Egg Harbor Twp, NJ 08234-7658
(609) 927-0418
✉tarsa@aol.com
1,2,3,4,9

THYROID DISORDERS

See also: Hypoparathyroidism

Thyroid Foundation of America
Ruth Sleeper Hall
RSL 350 40 Parkman St
Boston, MA 02114-2698
(800) 832-8321
(617) 726-8500
(617) 726-4136 (fax)
✉info@tsh.org (for thyroid questions)
✉admin@tsh.org
http://www.tfawev.org/pub/tfa
1,2,5,8

Thyroid Foundation of Canada
96 Mack St.
Kingston, ON CAN K7L 1N9
(613) 544-8364
(613) 544-9731 (fax)
✉thyroid@kos.net
http://www.home.ican.net/~!thyroid.Canada.html
1,2,3,7,8

TOOTH AND NAIL SYNDROME

See: Ectodermal Dysplasias

TORSION DYSTONIA, IDIOPATHIC

See: Dystonia

TOURETTE SYNDROME

See also: Attention Deficit Disorder; Obsessive-Compulsive Disorder

Tourette Syndrome Association
42-40 Bell Blvd.
Bayside, NY 11361-2820
(718) 224-2999
(718) 279-9596 (fax)
✉ tourette@ix.netcom.com
http://neuro.www2.mgh.harvard.edu/tsa/tsamain.nclk
1,2,4,5,6,7,8,9; Spanish materials

Tourette Syndrome Foundation of Canada
194 Jarvis St., Ste. 206
Toronto, ON CAN M5B 2B7
(800) 361-3120 (Canada only)
(416) 861-8398
(416) 861-2472 (fax)
✉ tsfc.org@sympatico.ca
http://www.tourette.ca
1,2,3,4,5,6,7,8,9; French materials

TOXIC PARALYTIC ANEMIA

See: Anemia, Aplastic

TOXOCARIASIS

National Toxicariasis Foundation Project Mustard Seed
815 Hillboro Rd.
Edwardsville, IL 62025
(618) 659-1212
(618) 656-3965
lmsjursen@hotmail.com
1,2,3,4,5,6,7,8,9

TRACHEOESOPHAGEAL FISTULA (TEF)

See: VACTERL Association

TREACHER COLLINS SYNDROME

See also: Craniofacial Disorders; Hearing Impairments

Treacher Collins Foundation
PO Box 683
Norwich, VT 05055
(800) 823-2055
(802) 649-3050
http://www.treachercollinsfnd.org
1,2,3,4,6

TREMOR

International Tremor Foundation
7046 W 105th St.
Overland Park, KS 66212-1803
(913) 341-3880
(913) 341-1296 (fax)
✉IntTremorFnd@worldnet.att.net
http://www.essentialtremor.org
1,2,3,4,5,7,8,9

TRICHODENTOOSSEOUS SYNDROME; TYPES I, II & III

See: Ectodermal Dysplasias

TRICHODYSPLASIA-ONYCHOGRYPOSIS-HYPOHIDROSIS-CATARACT

See: Ectodermal Dysplasias

KEY TO SERVICES

1 Periodical/newsletter
2 Informational materials
3 Networking/matching
4 Referrals to local resources
5 Local chapters
6 National conferences
7 National advocacy efforts
8 Fund research
9 Maintain research registry

National Resources for Specific Disabilities

TRICHOFACIOHYPOHIDROTIC SYNDROME
See: Ectodermal Dysplasias

TRICHONYCHODENTAL DYSPLASIA
See: Ectodermal Dysplasias

TRICHONYCHODYSPLASIA WITH XERODERMA
See: Ectodermal Dysplasias

TRICHOOCULODERMOVERTEBRAL SYNDROME
See: Ectodermal Dysplasias

TRICHOODONTOONYCHIAL DYSPLASIA
See: Ectodermal Dysplasias

TRICHOODONTOONYCHO-HYPOHIDROTIC DYSPLASIA WITH CATARACT
See: Ectodermal Dysplasias

TRICHOODONTOONYCHODERMAL SYNDROME
See: Ectodermal Dysplasias

TRICHOODONTOONYCHODYSPLASIA WITH PILI TORTI
See: Ectodermal Dysplasias

TRICHOPOLIODYSTROPHY
See: Menkes Disease

TRICHORHINOPHALANGEAL (TRP) SYNDROME
See: Ectodermal Dysplasias

TRICHOTILLOMANIA
See: Obsessive-Compulsive Disorder

TRIPHALANGEAL THUMBS-ONYCHODYSTROPHY-DEAFNESS
See: Ectodermal Dysplasias; Hearing Impairments

TRP SYNDROME, TYPE I
See: Ectodermal Dysplasias

TRPS SYNDROME, TYPE II
See: Ectodermal Dysplasias

TUBEROUS SCLEROSIS
See also: Autism; Epilepsy; Learning Disabilities

National Tuberous Sclerosis Association
8181 Professional Pl., Ste. 110
Landover, MD 20785-2226
(800) 225-6872
(301) 459-9888
(301) 459-0394 (fax)
✉ntsa@ntsa.org
http://www.ntsa.org
1,2,3,4,9;National volunteer support network.

TUBEROUS SCLEROSIS
See also: Autism; Epilepsy; Learning Disabilities

Tuberous Sclerosis Canada Sclérose Tubéreuse
2443 New Wood Dr.
Oakville, ON CA L6H 5Y3
(800) 347-0252
(905) 257-1997
✉jillian.dasilva@ablelink.org
http://www.sky.net/~adamse/tuberous.htm
1,2,3,4,7,8,9.

TURCOT SYNDROME
See: Brain Tumors; Cancer

TURNER SYNDROME
See also: Growth Disorders

Turner's Syndrome Society of Canada
814 Glencairn Ave.
Toronto, ON CAN M6B 2A3
(800) 465-6744
(416) 781-2086
(416) 781-7245 (fax)
✉tssincan@web.net
http://www.turnersyndrome.ca
1,2,3,4,5,6, French Materials

Turner's Syndrome Society of the US
1313 SE 5th St., Ste. 327
Minneapolis, MN 55414
(800) 365-9944
(612) 379-3607
(612) 379-3619 (fax)
✉shel@turner-syndrome-us.org
http://www.turner-syndrome-us.org
1,2,3,5,6,9; Spanish materials

TWIN-RELATED DISEASES

Conjoined Twins International
PO Box 10895
Prescott, AZ 86304-0895
✉jmsjr@northlink.com

Twin Hope
2592 West 14th St.
Cleveland, OH 44113
(216) 228-8887
twinhope@mail.ohio.net
http://www.twinhope.com
1,2,3,4,5,7,8,9

TWIN TO TWIN TRANSFUSION SYNDROME
See also: Twin-Related Diseases

Twin to Twin Transfusion Syndrome Foundation
411 Longbeach Parkway
Bay Village, OH 44140
(440) 401-8887 (urgent calls only)
(440) 899-8887
(440) 899-1184 (fax)
✉tttsfound@aol.com
http://www.tttsfoundation.org
1,2,3,4,5,7,8,9

TYROSINEMIA, HEREDITARY, HEPATORENAL TYPE
See: Tyrosinemia Type I

TYROSINEMIA TYPE I
See also: Kidney Disorders; Liver Disorders

Groupe Aide aux Enfants Tyrosinemiques du Quebec
3162 Rue Granville
Jonquiere, QC CAN G7S 2B9
(418) 548-1580
✉gerard.tremblay@sympatico.ca
http://www.members.xoom.com/Tyrosine/tyrosine.html
1,2,4,5,9; English/French materials; support available in Spanish.

TYROSYLURIA
See: Tyrosinemia I

UREA CYCLE DISORDERS
See: Metabolic Disorders

National Urea Cycle Disorders Foundation
4841 Hill St.
La Canada, CA 91011
(800) 386-8233
http://www.nucdf.org
1,2,3,4,6,7,8,9

UROLOGIC DISORDERS
See: Incontinence; Kidney Diseases, Hereditary; Kidney Disorders

UROSTOMY
See: Ostomy

URTICARIA PIGMENTOSA
See: Mast Csll Diseases

USHER SYNDROME
See also: Deaf-Blind; Hearing Impairments; Retinitis Pigmentosa; Visual Impairments

Usher Around The World
c/o Kathie Anderson
PO Box 17318
Minneapolis, MN 55417
(612) 729-4630 (V/TTY)
1,3

VACTERL ASSOCIATION
See also: Anorectal Malformations; CHARGE Association; Heart Disorders; Kidney Disorders; Limb Disorders; Spina Bifida

TEF/VATER International Support Network
c/o Greg and Terri Burke
15301 Grey Fox Rd.
Upper Marlboro, MD 20772
(301) 952-6837
1,2,3,7,8,9

VAN MEERKEREN I SYNDROME
See: Ehlers-Danlos Syndrome

VASCULAR MALFORMATIONS
See also: Arteriovenous Malformations (AVMs); Klippel-Trenaunay Syndrome; Lymphatic Malformations; Moyamoya Disease; Sturge-Weber Syndrome

National Vascular Malformations Foundation
8320 Nightingale
Dearborn Heights, MI 48127
(313) 274-1243
(313) 274-1393 (fax)
1,2,3,4,6

VASCULAR MALFORMATIONS
See also: Klippel Trenaunay Syndrome; Lymphatic Malformations; Moyamoya; Disease; Sturge-Weber Syndrome; Von Hippel-Lindau Syndrome

VATER ASSOCIATION
See: VACTERL Association

VELO-CARDIO-FACIAL SYNDROME
See also: CHARGE Association; Craniofacial Disorders; Heart Disorders

Northeast VCFS Support Group
2 Lansing Dr.
Salem, NH 03079
(603) 898-6332
MLADJA@aol.com
1,2,3,6,9; International educational foundation for research

VELO-CARDIO-FACIAL SYNDROME DH
See also: CHARGE Association; Craniofacial Disorders; Heart Disorders

Velo-Cardio-Facial Syndrome Parent Support Group
110-45 Queens Blvd.
Forest Hills, NY 11375-5501
(718) 261-8049
(718) 261-7346 (fax)
2,3,4,9

VENOUS MALFORMATIONS
See: Vascular Malformations

VENTILATOR USE

Citizens for Independence in Living & Breathing
78 Golfwood Hights
Toronto, ON CAN M9P 3M2
(416) 244-2248 (voice/fax)
2,3,4,6,7,9

International Ventilator Users Network
(IVUN)
4207 Lindell Blvd., #110
St Louis, MO 63108-2915
(314) 534-0475
(314) 534-5070 (fax)
✉gini_intl@msn.com
✉jfisc48232@aol.com
http://www.post-polio.org/IVUN.html
1,2,3,4,6,7,9

VENTRICULAR DEFECTS
See: Heart Disorders

VERMIS CEREBELLAR AGENESIS
See: Joubert Syndrome

VESTIBULAR DISORDERS
See also: Balance Disorders & Dizziness

Vestibular Disorders Association
PO Box 4467
Portland, OR 97208-4467
(800) 837-8428
(503) 229-8064 (fax)
✉veda@vestibular.org
http://www.vestibular.org
1,2,3,5,6; Spanish materials

VISUAL IMPAIRMENT/ HEARING IMPAIRMENT
See: Deaf-Blind

VISUAL IMPAIRMENTS
See also: Albinism; Glaucoma; Macular Diseases; Retinitis Pigmentosa; Retinoblastoma; Retinopathy of Prematurity; Septo-Optic Dysplasia; Usher Syndrome

American Council of the Blind
1155 15th St NW, Ste.720
Washington, DC 20005
(800) 424-8666 (3–5:30 p.m. EST)
(202) 467-5081
(202) 467-5085 (fax)
✉info@acb.org
http://www.acb.org
1,2,4,5,6

American Foundation for the Blind
11 Penn Plaza, Ste. 300
New York, NY 10001
(800) 232-3044
(212) 502-7600
(212) 502-7662 (TTY)
✉afbinfo@afb.org
http://www.afb.org/afb
1,2,4,5,6,8

Blind Children's Center
4120 Marathon St.
Los Angeles, CA 90029
(800) 222-3566
(800) 222-3567 (CA only)
(323) 664-2153
(323) 665-3828 (fax)
✉info@blindchildrenscenter.org
http://www.blindchildrenscenter.org
1,2,3,4,8 Spanish materials

Blind Childrens Fund
4740 Okemos Rd.
Okemos, MI 48864
(517) 347-1357
(517) 347-1459 (fax)
✉blindschildrensfund@aol. com
http://www.blindchildrensfund.org
1,2,3, (networking only), 4,5,6

Blind Children's Fund Resource Center
2971 53rd St. SE.
Auburn, WA 98092
(206) 735-6350 (voice/fax)
✉blindchildrensfund@charitiesusa.com
1,2,4,6

Braille Institute of America
741 N Vermont Ave.
Los Angeles, CA 90029
(213) 663-1111
✉julief@braileinstitute.org
http://www.brailleinstitute.org

Canadian National Institute for the Blind
1929 Bayview Ave.
Toronto, ON CAN M4G 3E8
(416) 486-2500
(416) 480-7417 (TTY)
(416) 480-7699 (fax)
✉marjerb@east.cnib.ca
1,2,3,4,6,7,8; French materials

Council of Citizens with Low Vision International
6511 26th St. W.
Bradenton, FL 34207
(800) 317-2258
(941) 755-3846
1,2,3,4,7,8

Council of Families with Vision Impairment
6212 W. Franklin St.
Richmond, VA 23226
(804) 288-0395
1,2,3,4,6,7

The Lighthouse National Center for Vision and Child Development
111 East 59th St.
New York, NY 10022
(800) 334-5497(voice)
(212) 821-9200 (voice)
(212) 821-9713 (TTY)
(212) 821-9705 (fax)
✉mbeck@lighthouse.org
http://www.lighthouse.org
1,2,4,5,7; Spanish materials

National Association for Parents of the Visually Impaired
PO Box 317
Watertown, MA 02471
(800) 562-6265
(617) 972-7441
(617) 972-7444 (fax)
✉napvi@perkins.pvt.k12.ma.us
http://www.spedex.com/napvi
1,2,3,5,7; Spanish materials

National Association for Visually Handicapped
22 W 21st St., 6th Fl.
New York, NY 10010
(212) 889-3141
(212) 727-2931 (fax)
✉staff@navh.org
http://www.navh.org
1,2,5,6; Spanish/Russian materials;large-print lending library.

National Braille Press
88 St. Stephen St.
Boston, MA 02115
(800) 548-7323
(617) 266-6160
(617) 437-0456 (fax)
✉orders@nbp.org
http://www.npb.org
2

National Organization for Parents of Blind Children
1800 Johnson St.
Baltimore, MD 21230
(410) 659-9314
(612) 869-4599 (BBS)
(410) 685-5653 (fax)
✉nfb@iamdigex.net
http://www.nfb.org
1,2,3,4,5,6,7 Spanish materials.

Prevent Blindness America
500 E Remington Rd.
Schaumburg, IL 60173-4557
(800) 331-2020
(847) 843-2020
(847) 843-8458 (fax)
⊠74777.100@compuserve.com
http://www.prevent_blindness.org
1,2,5,6,7,8; Spanish materials

Recording for the Blind & Dyslexic
20 Roszel Rd.
Princeton, NJ 08540
(609) 520-8079
(609) 520-7990 (fax)
⊠info2rfbd.org
http://www.rfbd.org
2

The Lighthouse National Center for Vision and Child Development
111 East 59th St.
New York, NY 10022
(800) 829-0500
(212) 821-9200
(212) 821-9713 (TTY)
(212) 821-9705 (fax)
⊠mbeck@lighthouse.org
http://www.lighthouse.org
1,2,4,5,7; Spanish materials

Vision World Wide, Inc.
5707 Brockton Dr., Ste. 302
Indianapolis, IN 46220-5481
(800) 431-1739
(317) 254-1332
(317) 251-6588 (fax)
⊠visionww@aol.com
http://www.visionww.org
1,2,5

VITAMIN B12 METABOLISM; INBORN ERROR OF

See: Cobalamin (B12) Defiency

VITILIGO

The Canadian Vitiligo Society
Dr. Danuta Pawlowski
Western General Hospital
8th Fl, Rm 542
399 Bathurst St
Toronto, Ontario CAN M5T 2S8
(416) 603-5721

National Vitiligo Foundation
611 S. Sleishel Ave.
Tyler, TX 75701
(903) 531-0074
(903) 525-1234 (fax)
⊠vitiligo@trimofran.org
http://www.vitiligofoundation.org
1,2,3,5,6,7,8,9

VON GIERKE DISEASE

See: Glycogen Storage Diseases

VON HIPPEL-LINDAU SYNDROME

See also: Ataxia; Balance Disorders & Dizziness; Brain Tumors; Visual Impairments

Von Hippel-Lindau Syndrome Family Alliance
171 Clinton Rd.
Brookline, MA 02445-5815
(800) 767-4845
(617) 232-5946
(617) 734-8233
⊠info@vhl.org
http://www.vhl.org
1,2,3,4,5,7,8,9; Spanish/French/German/Dutch/Italian materials.

VON RECKLINGHAUSEN DISEASE

See: Neurofibromatosis

VON WILLEBRAND DISEASE

See: Hemophilia

VROLIK DISEASE, TYPE II

See: Osteogenesis Imperfecta

WALBAUM-DEHEANE-SCHLEMMER SYNDROME

See: Ectodermal Dysplasias

WALKER-WARBURG SYNDROME

See: Hydrocephalus; Lissencephaly

WARBURG SYNDROME

See: Hydrocephalus; Lissencephaly

WEBER SYNDROME

See:Sturge-Weber Syndrome

WEGENER GRANULOMATOSIS

See also: Immune Disorders

Wegener's Granulomatosis Support Group, Inc (International)
PO Box 28660
Kansas City, MO 64188-8660
(800) 277-9474
(816) 436-8211(fax)
⊠wgsg@wgsg.org
http://www.wgsg.org
1,2,3,4,5,6,8,9

WERDNIG-HOFFMAN DISEASE

See:Spinal Muscular Atrophy

WERLHOF DISEASE

See: Purpura, Idiopathic Thrombocytopenia (ITP)

WERMER SYNDROME

See: Multiple Endocrine Neoplasia I

WERNER SYNDROME

See: Progeria

WHISTLING FACE SYNDROME

See: Freeman-Sheldon Syndrome

WHISTLING FACE-WINDMILL VEIN HAND SYNDROME

See: Freeman-Sheldon Syndrome

WHITE MATTER DISORDERS

See: Leukodystrophy

WHITE SPOT DISEASE

See: Vitiligo

WHITNALL-NORMAN SYNDROME

See: Norrie Disease

WILLIAMS SYNDROME

See also: Autism; Attention Deficit Disorder; Growth Disorders; Heart Disorders; Learning Disabilities; Noonan Syndrome

Canadian Association for Williams Syndrome
PO Box 2115
Vancouver, BC CAN V6B 3T5
(604) 852-2662
(604) 855-0032 (fax)
⊠sev@uniserve.com
http://www.bmts.com/~williams/
1,2,3,4,5,7,8,9

Williams Syndrome Association
PO Box 297
Clawson, MI 48017-0297
(241) 541-3630
(241) 541-3631 (fax)
⊠WSAoffice@aol.com
http://members.aol.com/BobHazard/wsc.html
1,2,3,4,5,6,8,9; DNA research bank, annual music camp

WILLIAMS-BEUREN SYNDROME

See: Williams Syndrome

WILMS TUMOR

See: Kidney Disorders

WISKOTT-ALDRICH SYNDROME

See: Immune Disorders; Purpura, Idiopathic Thrombocytopenia

WOLF SYNDROME

See: Wolf-Hirshhorn Syndrome

WOLF-HIRSCHHORN SYNDROME

4p- Parent Network
913 Herons Run Ln.
Woodbridge, VA 22191
(703)497-2807
⊠tombecr@aol.com
http://members.aol.com/lbent503/whs
1,2,3,6,9

Wolf-Hirschhorn Syndrome Support Group and Newsletter
c/o Brenda Grimmett
5536 Virginia Ct.
Amherst, OH 44001
(440) 282-1460
⊠bgrimmett@eriecoast.com
http://members.aol.com/lbent503/whs
1,2,3,4,6,9

X-LINKED COPPER DEFICIENCY

See: Menkes Disease

X-LINKED COPPER MALABSORPTION

See: Menkes Disease

X-LINKED MYOTUBULAR MYOPATHY

See: Myotubular Myopathy, X-Linked; Muscular Dystrophy

XANTHOGRANULOMATOSIS, JUVENILE

See: Histiocytosis

XERODERMA PIGMENTOSUM

Canadian Organization of Rare Disorders (CORD)
PO Box 814
Coaldale Alberta, CAN T1M 1M7
(403) 345-3948
(403) 345-4544 (fax)
⊠cord@bulli.com
http://www.bulli.com/~cord
1,4,5,6

Easter Seals Society
1185 Eglington Ave., Ste. 800
Don Mills, Ontario CAN M3C 3P2
(416) 421-8377
(416) 696-1035 (fax)
⊠info@easterseals.org
http://www.easterseals.org

XERODERMA-TALIPES-ENAMEL DEFECT

See: Ectodermal Dysplasias

ZANIER-ROUBICEK SYNDROME

See: Ectodermal Dysplasias

ZELLWEGER SYNDROME

See: Leukodystrophy

ZIEHEN-OPPENHEIM DISEASE

See: Dystonia

MATCHING RESOURCES

This directory of "Matching Resources"—both national and international—can help some parents who have children with extremely rare conditions or unique combinations of disabilities. Others may be dealing with unique family situations, such as single parenting, raising twins, or adoption. These networking organizations do parent-to-parent matching based on children's disabilities and, in some cases, other unique family situations. Most maintain ongoing contact with other groups worldwide.

Unless otherwise noted, all services are provided free of charge. This symbol, ⊠, indicates an e-mail address. All international calls from the US or Canada require dialing 011 before the number. Please be aware of timezone differences when making any calls, particularly international ones. (Unless otherwise noted, telephone numbers are for voice only.)

Association of Birth Defect Children
930 Woodcock Rd., Ste. 225
Orlando, FL 32803
(800) 313-2232 (24-hour registry line)
(407) 245-7035
(407) 895-0824 (fax)
http://www.birthdefects.org
⊠abdc@birthdefects.org

Association of Genetic Support/ Australia
740 66 Albion St.
Surry Hills, NSW 2010
Australia
(61) 2211 1462

Canadian Organization for Rare Disorders (CORD)
PO Box 814
Coaldale, AB CAN
T1M 1M7
(877) 302-7273
(403) 345-3948
(403) 345-4544
http://www.bulli.com/~cord/
⊠cord@bulli.com

Easter Seal Society
250 Ferrand Dr., Ste. 200
at: Eglinton Ave.
Don Mills, ON CAN M3C 3P2
(416) 421-8377
(416) 696-1035 (fax)
http://www.easterseals.org
⊠info@easterseals.org

The Centre for Rare Diseases and Disabilities
Copenhagen:
Bredgrade 25
Sct. Annae Passage,
opg F, 5th Fl.
DK-1260 Copenhagen K
Denmark
(45) 33 91 40 20
(45) 33 91 40 19 (fax)

MUMS
Mothers United for Moral Support
c/o Julie Gordon
150 Cusler Ct.
Green Bay, WI 54301-1243
(920) 336-5333
(920) 339-0995 (fax)
http://www.waisman.wisc.edu/~rowley/mums/home.htmlx
⊠mums@netnet.net

National Organization for Rare Disorders (NORD)
100 Rt. 37, PO Box 8923
New Fairfield, CT 06812-8923
(800) 999-6673 (voice)
(203) 746-6518 (voice)
(203) 746-6927 (TTY)
(203) 746-6481 (fax)
http://www.rarediseases.org
⊠orphan@rarediseases.org

NPPSIS
National Parent to Parent Support and Information Service
PO Box 907
Blue Ridge, GA 30513
(800) 651-1151
(828) 494-5415
(828) 494-5414 (fax)
http://www.nppsis.org
⊠nppsis@elijay.com

Parent-to-Parent Link Program
The Easter Seal Society, Ontario
1185 Eglington Ave., Ste. 800
North York, ON CAN M3C 3C6
(416) 421-8377
(416) 696-1035 (fax)
http://www.easterseals.org
⊠info@easterseals.org

Rare Chromosome Disorder Group
c/o Edna Knight
Harrow Weald
160 Locket Rd.
Middlesex
England HA3 7NZ
(01144) 81-963-3557 (voice, evening)

Research Trust for Metabolic Diseases in Children (RTMDC)
Golden Gates Lodge
Weston Rd., Crewe
Cheshire, England CW2 5XN UK
(44) 1270 250221
(44) 1270 250244 (fax)
http://www.medhlp.netusa.net/agsg/agsg1183/htm

OTHER RESOURCES

Search & Respond
c/o Exceptional Parent Magazine
555 Kinderkamack Rd.
Oradell, NJ 07649-1517
(201) 634-6550
(201) 634-6570 (fax)
http://www.eparent.com

Exceptional Parent magazine accepts letters from parents and professionals searching for information, networking, or advice from others on a disability or related problem. Some are selected for publication in our monthly Search column. Anyone offering a suggestion may write a Respond letter, which will be forwarded and may also be published.

CORPORATE PROFILE

MetLife Financial Services

COMPANY MetDESK
Metropolitan Life Insurance Co.
One Madison Avenue- Area 5E
New York, NY 10010
Tel: 1-212-578-8532
Fax: 1-212-578-3164
Website: www.metlife.com/specialneeds/
E-mail: dmharmon@metlife.com

FOUNDER Nadine O. Vogel, MBA

MANAGER David M. Harmon, CLU, ChFC, MSW

PRODUCTS AND SERVICES: MetDESK, Division of Estate Planning for Special Kids was established to extend MetLife's traditional commitment to public service to families of children with special needs. MetDESK is committed to helping families through the maze of legal and financial complexities surrounding planning for the future of a child or dependent with special needs. This includes preserving government benefits, meeting long term care needs, and structuring a plan to provide cash when it's needed most.

FOUNDER'S MESSAGE: According to Assistant Vice President and MetDESK founder Nadine O. Vogel, the strict training and continuing education requirements of the MetLife financial services representative participating in this marketplace is unique in the industry. "Special needs planning is too complex for the untrained or marginally trained financial services representative or even a general estate planning attorney. A broad one or two day training overview will not keep pace with the constant changes in federal and state government benefit laws, future trends in special needs planning, and innovations in planning techniques," she explains. In addition, 70 percent of MetDESK specialists from around the country are either parents of children with special needs or have close relatives with special needs. Vogel continues, "Parents of children with special needs feel more comfortable dealing with people who face similar issues on a day to day basis.

RECENT AWARD & ACTIVITIES: MetLife Financial Services is the 1999 Winner of the National Business & Disability Council's Valued Customer Gold Award of Honor. The Award recognizes MetLife's leadership and responding to the special needs of families of children or dependents with disabilities. The MetDESK program was hailed by business and the community at large for its efforts on behalf of people with disabilities as valued customers. Additionally, MetLife is a proud sponsor of the first annual World Congress & Exposition on Disabilities, November 2000, Atlanta, Georgia

METLIFE'S VITAL STATISTICS: Headquartered in New York City since 1868, MetLife is a leading provider of insurance and financial products and services to a broad spectrum of individual and group customers. The company, with approximately $360.7 billion of assets under management as of year-end 1998, provides individual insurance and investment products to approximately 9 million households in the U.S. MetLife also serves over 33 million people by providing group insurance and investment products to corporations and other institutions. For more information about MetLife, please visit the company's Web site at www.metlife.com.

UNIQUE ATTRIBUTES: MetDESK's management has deep roots in advocacy. This commitment and training sets the foundation for MetDESK specialists to help families with children and dependents with special needs plan for their financial futures.

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It's important that you take the time today to provide for your child's tomorrow.

At MetLife we know that parenting children with special needs takes exceptional planning. That's why we created **MetDESK** (Division of Estate Planning for Special Kids), staffed by a group of specialists who can help you navigate the many financial and legal issues involved in providing quality lifetime care for your child. Each member brings indepth knowledge and understanding of families with special needs children.

In fact, MetDESK recently received the *National Business & Disability Council's Valued Customer Gold Award of Honor* in recognition of MetLife's leadership in responding to the special needs of families of children with disabilities.

Life Advice

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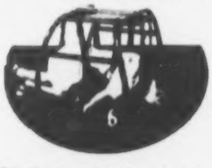

FOR MORE INFORMATION:
REDBARN ENTERPRISES, INC.
6225 N. 16th AVE.
PHOENIX, AZ 85015

FAX: 1-602-242-9211

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OR VISIT OUR WEB SITE AT
WWW.RFBD.ORG

Circle #109

74

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SDTC

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914-794-1400, extension 1444
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CHIEF EXECUTIVE OFFICER
Mr. Barry Romich

CHIEF OPERATING OFFICER
Mr. Don Battershell

DIRECTOR OF CUSTOMER SERVICE
Ms. Lisa Fannin

Language Support Success

ABOUT OUR PRODUCTS Prentke Romich Company (PRC) designs, manufacturers and supports augmentative and alternative communication aids. Our products are designed to enable people with disabilities to reach their full potential through effective communication. Our communications devices include AlphaTalker, DeltaTalker, Vanguard, Axs 1600 and the recently introduced Pathfinder plus a full range of computer access tools and accessories.

All of our communications devices utilize Minspeak, one of the most widely used language systems in the field and available exclusively through PRC. Because it is based on the natural structure of language, Minspeak allows users to build and improve their communications capability over time.

MISSION .... to help people with disabilities achieve their potential in educational, vocational and personal pursuits. We accomplish this mission by providing quality language and assistive technology products to people with disabilities, their families and professionals.

UNIQUE ATTRIBUTES PRC is a leader in providing communications solutions for one simple reason. We define our success by the success of our clients. At any gathering of AAC users, people using PRC products stand out as the best communicators. In fact, we have more than 100 people using our devices who regularly serve as "Ambassadors" for PRC by speaking and answering questions at national and regional conferences.

We also recognize that communications is a very human endeavor so our commitment to your success extends beyond providing the best technology and language systems. We maintain a national network of consultants, speech and language experts, who can help you select and learn to use the right AAC products. We provide equipment for rental or trial use, customer service support, technical support and assistance in obtaining funding for our products. And today, we are a leader in providing online information and training services to make our products affordable and accessible.

easy yet powerful communication aids by prentke romich company 800-262-1933 www.prentrom.com

TIME SAVERS

INNOVATIONS SUCH AS DISTANCE LEARNING, LANGUAGE ACTIVITY MONITOR (LAM), AND THE PRC PICTURE SET ALLOW PROFESSIONALS TO SPEND THEIR TIME WHERE IT REALLY MATTERS.

PRC

We know you didn't go into your profession for the paperwork.

Circle #106

Parent to Parent Programs

Parent to Parent (P-P) programs provide informational and emotional support to parents who have a child, adolescent or adult family member with special needs. P-P programs offer an important connection for a parent who is seeking support for a specific disability issue, by matching him or her with a trained "veteran" parent who has already "been there." Because the two parents share so many common concerns and interests, the support given and received is often uniquely meaningful. Such one-to-one relationships provide more intimate and individualized support than can be found in most traditional parent support groups.

P-P programs have been providing one-to-one matches for more than 25 years. The major components are screening and training of veteran parents, careful matches based on family and disability issues, and follow-up support for each match. Many P-P programs also offer a range of other activities including parent groups for education and support, social events, resource libraries, and services for other family members.

Some states have a Statewide P-P program that offers training and technical assistance to local programs. These Statewide P-P programs often have extensive computerized databases that allow them to make a Statewide match when an appropriate local match cannot be found.

INTERNATIONAL PARENT TO PARENT CONFERENCE

Every other year, parents, P-P program directors, and other professionals in the families and disability field, gather at the International Parent to Parent Conference. The Tenth International Parent to Parent Conference will be held in Reno, Nevada May 5-7, 2000. For further information, please contact: Nevada Parent Network, College of Education/285, Reno, NV 89557-0082; telephone: (775) 784-4921.

USING THIS DIRECTORY

This directory contains P-P programs that provided at least both an address and a telephone number. (Unless indicated, all telephone numbers are for voice only.) Statewide P-P programs have an asterisk (*) by their names, and local programs that are affiliated with the Statewide program are not listed seperately, and gave EXCEPTIONAL PARENT magazine permission for contact information to be included in the EXCEPTIONAL PARENT *Resource Guide*. If you are looking for a local program in a state that has a Statewide program, please contact the Statewide program for contact information. If you do not find a local program in your community, or if you wish to add or make revisions to this list, please contact the Beach Center on Families and Disability, 3111 Haworth Hall, University of Kansas, Lawrence, KS 66045; telephone: (785) 864-7600 (voice/TDD); fax: (785) 864-7605.

When available, World Wide Web sites and e-mail addresses have been included. Web sites are listed with the standard **http://** before each. E-mail addresses are indicated by the symbol, ✉. (Unless otherwise indicated, all telephone numbers are for voice only.)

ALABAMA

Friends for Life
Auburn United Methodist Church
137 S. Gay St.
Auburn, AL 36830
(334) 826-8800

Special Education Action Commitee
Birmingham Outreach Office
25 W. Oxmoor Rd., Ste. 50
Birmingham, AL 35209
(205) 941-0313 (V/TTY)
(205) 941-0987 (fax)

The Arc of Morgan County
401 14th St. SE, Ste. 4-E
Decatur, AL 35601
(205) 355-6192
(256) 350-4502 (fax)

Special Education Action Commitee
Huntsville Outreach Office
3322 S. Memorial Parkway, Ste. 22
Huntsville, AL 35801
(800) 222-7322 (AL only)
(256) 882-3974 (fax)
✉seachsv@traveller.com
http://www.hsv.tis.net/~seachsv

Special Education Action Commitee
600 Bel Air Blvd., Ste. 210
Mobile, AL 36606
(800) 222-7322 (AL only)
(334) 478-1208 (V/TTY)
(334) 473-7877 (fax)
✉seacofmobile@zebra.net
http://www.hsv.tis.net/~seachsv

The Arc of Morgan County
2046 Beltline Hwy., Ste. 4
Decatur, AL 35601
(205) 355-6192

ARKANSAS

Parent to Parent
Arc of Arkansas
2000 Main St.
Little Rock, AR 72206
(501) 375-7770
(501) 372-4621 (fax)

ARIZONA

Pilot Parent Partnerships
4750 N. Black Canyon, Ste. 101
Phoenix, AZ 85017
(800) 237-3007 (AZ only)
(602) 242-4366 (voice/TTY)
(602) 242-4306 (fax)

CALIFORNIA

H.E.A.R.T.S. Connection Family Resource Center
3101 N. Sillect Ave., Ste.115
Bakersfield, CA 93308
(661) 328-9055, ext 282
(661) 328-9940 (fax)

Family Resource Network
PO Box 3697
Chico, CA 95927
(916) 894-5879

Humboldt Child Care Council
The Special Needs Connection
805 7th St.
Eureka, CA 95501
(800) 795-3554 (CA only)
(707) 444-8293
(707) 444-8298 (fax)
✉snc@humboldtl.com

Exceptional Parents Unlimited
Family Resource Center
4120 N. First St.
Fresno, CA 93726
(559) 229-2000
(559) 229-2956 (fax)
✉epu1@cybergate.com

Comfort Connection
Family Resource Center
12361 Lewis St., Ste. 101
Garden Grove, CA 92840-4683
(888) 372-2229 (local only)
(714) 748-7491
(714) 748-8149 (fax)

Carolyn Kordich
Family Resource Center
PO Box 216
Harbor City, CA 90710-0216
(310) 325-7288 (voice/fax)
✉ckfrc@worldnet.att.net

Families Caring for Families
Family Resource Center
113 W. Pillsbury St., Ste. A1
Lancaster, CA 93534
(805) 949-1746
(805) 948-7266 (fax)

South Central Los Angeles Regional Center For Developmentally Disabled Persons, Inc.
2160 W. Adams Blvd.
Los Angeles, CA 90018
(213) 734-1884
(213) 730-0793 (fax)

CARE
Family Resource Center
1350 Arnold Dr., Ste. 203
Martinez, CA 94553
(800) 281-3023 (Bay Area Only)
(925) 313-0999
(925) 370-8651 (fax)

Challenged Family Resource Center
623 W. 13th St., Bldg. H
Merced, CA 95340
(209) 385-8454
(209) 385-8483 (fax)
✉dkuneck@aol.com

Family Focus Resource Center
18111 Nordhoff St.
Northridge, CA 91330-8265
(818) 677-5575
(818) 677-5574 (fax)
✉family.focus@csun.edu
http://www.csun.edu/~ffrc/family_html.htm

Rainbow Connection
500 Esplanade Dr., Ste. 500
Oxnard, CA 93030
(800) 332-3679
(805) 485-9643
(805) 988-9521 (fax)
✉jordan@jetlink.net

Warmline Family Resource Center
PO Box 160
Rancho Cordova, CA 95670
(800) 660-7995 (Six-City area)
(916) 631-7995
(916) 942-2157 (fax)

Matrix Family Resource Center of the North Bay
5440 State Farm Dr., #3
Rohnert Park, CA 94928
(707) 586-3314
(707) 584-3438 (fax)
✉SonomaCo@matrixparents.org
http://www.mat.ixparents.org

Peaks and Valleys
Family Resource Center
1145 Acosta St.
Salinas, CA 93905
(800) 400-2937
(891) 424-2937
(831) 771-9132 (fax)
✉peaks@monterey.k12.ca.us

Early Start Family Resource Network
PO Box 6127
San Bernardino, CA 92412-6127
(800) 974-5553 (local only)
(909) 890-3103
(909) 890-3371 (fax)
✉esfrn@gte.net
http://www.inlandrc.org

Exceptional Family Resource Center
9245 Sky Park Ct., Ste. 130
San Diego, CA 92123
(877) 268-8252 (CA only)
(619) 292-9092
(619) 268-4275 (fax)
✉efrc@mail.sdsu.edu

Parent Helping Parents
594 Monterey Blvd.
San Francisco, CA 94127-2416
(415) 841-8820
(415) 841-8824 (fax)

Support for Families of Children with Disabilities
2601 Mission St., #710
San Francisco, CA 94110
415) 282-7494
(415) 282-1226 (fax)
✉sfcdmiss@aol.com

MATRIX: Parent Network and Family Resource Center
94 Galli Dr. Ste. C
Novato, CA 94903
(415) 884-3535
(415) 884-3555 (fax)
✉matrix@matrixparents.org
http://www.matrixparents.org

Family Support Network
1850 E. 17th St., Ste. 104
Santa Ana, CA 92705
(714) 543-7600
(714) 543-2766 (fax)
✉fsn4u@juno.com

United Cerebral Palsy Association of Orange County
3010 W. Harvard St.
Santa Ana, CA 92704-3914
(714) 557-1291
(714) 546-0943 (fax)

Family First Program
Alpha Resource Center
4501 Cathedral Oaks Rd.
Santa Barbara, CA 93110
(805) 683-2145
(805) 967-3647 (fax)
✉arcofsb@silcom.com

Parents Helping Parents
The Family Resource Center
3041 Olcott St.
Santa Clara, CA 95054-3222
(408) 727-5775
(408) 727-0182 (fax)
✉info@php.com
http://www.php.com

Special Connections Family Resource Ctr
984 Bostwick Ln.
Santa Cruz, CA 65062
(831) 464-0669
(831) 464-0779 (fax)

Phase One
Arc Sonoma County
PO Box 219
Santa Rosa, CA 95402-0219
(877) 859-9246
(707) 578-6070
(707) 578-0813 (fax)

Family Resource Network
5250 Claremont Ave., 235
Stockton, CA 95207
(800) 847-3030
(209) 472-3674
(209) 472-3673 (fax)

The Family and Professional Resource Center
21231 Hawthorne Blvd.
Torrance, CA 90503
(310) 543-0691
(310) 316-8843 (fax)
✉nancy@hddf.com

The Parents' Place
Family Resource Center
1502 W. Covina Pkwy., Ste. 108
West Covina, CA 91790-2708
(800) 422-2022
(626) 856-8861
(626) 337-2736 (fax)
✉empower@gte.net
http://www.parentsplace.net

COLORADO

Speech, Language, & Hearing Center
University of Colorado at Boulder
Campus Box 409
Boulder, CO 80309-0409
(303) 492-5375
(303) 492-1355 (TTY)
(303) 492-3274 (fax)
✉susan.moore@colorado.edu
http://www.colorado.edu/slhs
dowell@spot.colorado.edu

Parents Encouraging Parents
96 Gordon Ln.
Castle Rock, CO 80104
(303) 866-6846
(303) 688-6387 (fax)

OASIS, Inc.
1120 N. Circle Dr., Ste. 19
Colorado Springs, CO 80909
(719) 635-8722
(719) 577-9482 (fax)
✉oasis@juno.com

Resources for Young Children and Families, Inc.
1120 N. Circle Dr., Ste. 19
Colorado Springs, CO 80909
(719) 577-9190
(719) 577-9482 (fax)
http://www.rycf.org

Colorado Consortium of Intensive Care Nurseries United Parents (UP!)
1056 E.19th Ave. B535
Denver, CO 80218
(303) 861-6557
(303) 764-8092 (fax)
✉McGinley.Pandora@ex.tchden.org

Denver Early Childhood Connections
124 W. 5th Ave.
Denver, CO 80204
(303) 744-9193
(303) 744-9502 (fax)

El Groupo Vida
777 Bannock Mail Code 1701
Denver, CO 80204
(303) 436-3269

Little People of America
Front Range Chapter
7117 E. Euclid Dr.
Englewood, CO 80111
(303) 740-8555

Parent Support Group of Littleton and Auora
7600 E. Arapahoe, Ste. 219
Englewood, CO 80112
(303) 773-0044
(303) 773-8780 (fax)

The Disabiltity Connection and RAFT, Larimer County's Early Childhood Connection
PO Box 270714
Ft Collins, CO 80527
(970) 229-0224
(970) 229-0242 (fax)
✉bstuts@fomet.org

Effective Parents Project, Inc
115 N. Fifth St., Ste.540
Grand Junction, CO 81501
(970) 241-4068
(970) 241-3725 (fax)

Mile High Down Syndrome Association
PO Box 620847
Littleton, CO 80162
(303) 797-1699
(303) 347-2938 (fax)
✉mhdsa@aol.com

Delta/Montrose/Ouray Parent to Parent
2091 E. Locust Rd.
Montrose, CO 81401
(970) 249-2878
(970) 252-0544 (fax)
✉children@gj.net

HELP Parent Support Group Hope & Education for Loving Parents
378 S. Falcon
Pueblo West, CO 81007
(719) 545-2282
(719) 547-1282 (fax)
✉fastgram@aol.com

Parents Supporting Parents
PO Box 2656
Vail, CO 81658
(970) 926-6015 (phone/fax)

Parents Supporting Parents of Garfield and Pitkin County
PO Box 784
Silt, CO 81652
(970) 876-5768
(970) 876-5204 (fax)

CONNECTICUT

Parent to Parent Network of Connecticut
The Family Center
Dept. of Connecticut Children's Medical Center
282 Washington Ave.
Hartford, CT 06106
(860) 545-9021
(860) 545-9002 (TTY)
(860) 545-9201 (fax)
✉mcole@ccmckids.org
http://www.ccmckids.org

DELAWARE

Parent Information Center of Delaware, Inc.
700 Barksdale Rd., Ste. 6
Newark, DE 19711
(302) 366-0152
(302) 366-0276 (fax)
✉PEP700@aol.com

FLORIDA

Family Network on Disabilities of FL, Inc.
2735 Whitney Rd.
Clearwater, FL 33760
(800) 825-5736 (FL only)
(727) 523-1130 (voice/TTY)
(727) 523-8687 (fax)
✉fnd@gate.net
http://fndfl.org

Parent to Parent of Palm Beach County
1201 Australina Ave.
Riviera Beach, FL 33404
(561) 842-3213

GEORGIA

Parent to Parent of Georgia
2872 Woodcock Blvd., Ste. 230
Atlanta, GA 30341
(800) 229-2038 (GA only)
(770) 451-5484
(770) 458-4091 (fax)
info@parenttoparentofga.org
http://www.parenttoparentofga.org

HAWAII

Hawaii Down Syndrome Congress
419 Keoiana St., Ste. 604
Honolulu, HI 96815
(808) 949-1999
(808) 536-3765 (fax)
✉comkay@aol.com

IDAHO

Parents Reaching Out to Parents
2195 Ironwood Ct.
Coeur d'Alene, ID 83814
(208) 769-1409
(208) 769-1430 (fax)

Palouse Area Parent to Parent
2714 8th Ave.
Lewiston, ID 83501
(208) 746-8599 (tel/fax)
✉irel102w@wonder.cdc.gov

ILLINOIS

Archway, Inc.
2751 West Main
Carbondale, IL 62903
(618) 549-4442
(618) 549-0231 (fax)

Southern Illinois Child and Family Connections
1108 W. Willow
Carbondale, IL 62903
(888) 340-6702
(618) 549-8137 (fax)

Developmental Services Center
1304 W. Bradley
Champaign, IL 61821
(217) 359-0287
(217) 356-9851 (fax)

Parent to Parent Network
1530 Lincoln Ave.
PO Box 587
Charleston, IL 61920
(217) 348-0127
(217) 348-0740 (fax)

Child and Family Connections
1757 W. 95th St.
Chicago, IL 60643
(773) 233-1799
(773) 233-2011 (fax)

Family Resource Center on Disabilities
20 E Jackson Blvd., Ste. 300
Chicago, IL 60604
(800) 952-4199 (IL only)
(312) 939-3513
(312) 939-7297 (fax)

Next Steps-Parents Reaching Parents
100 W. Randolph, Ste. 8-100
Chicago, IL 60601
(312) 814-4042 (V/TTY)
(312) 814-5849 (fax)
✉caroldors@aol.com

Greater Interagency Council Parent to Parent Support Network
925 W.175th St.
Homewood, IL 60430
(708) 799-2718
(708) 799-7974 (fax)

National Association for Down Syndrome (NADS)
PO Box 4542
Oak Brook, IL 60522-4542
(630) 325-9112
(630) 325-8842 (fax)

INDIANA

Down Syndrome Association of Central Indiana
10792 Downing St.
Carmel, IN 46033-3869
(317) 574-9757

Down Syndrome Support Association of Southern Indiana (DSSASI)
PO Box 3262
Clarksville, IN 47131
(812) 948-5182

Down Syndrome Association of NWI
2927 Jewett Ave.
Highland, IN 46322
(219) 838-3656
(219) 838-6959 (fax)
✉dsa@netnitco.net

Family Resource Center of Southeast Indiana
4101 Timberview Rd.
West Harrison, IN 47060
(812) 637-1445

First Direction
PO Box 4234
Lafayette, IN 47903
(765) 742-0169

First Steps Early Interventions New Horizons Rehabilitation
PO Box 98
Batesville, IN 47006
(812) 934-4528 (V/TTY)
(812) 934-2522 (fax)

First Steps for Families
500 8th Ave.
Terre Haute, IN 47804
(812) 231-8342
(812) 231-8419
(812) 231-8420
(812) 231-8208 (fax)
✉famnetwork@aol.com

Future Choices
309 N. High St.
Muncie, IN 47305
(765) 741-3494
(765) 741-8333 (fax)

Indiana Parent Information Network
4755 Kingsway Dr., Ste. 105
Indianapolis, IN 46205
(317) 257-8683
(317) 251-7488 (fax)
✉familynet@aol.com
http://www.ai.org/ipin

ATTIC Inc.
PO Box 2441
2758 B E. Pine Hill Dr.
Vincennes, IN 47591
(800) 962-8842 (V/TTY)
(812) 886-0575 (V/TTY)
(812) 886-1128 (fax)
✉inattic2@aol.com

Knox County Advocates
1806 Indiana Ave.
Vincennes, IN 47591
(812) 882-0375
(812) 886-0575
(812) 886-1128 (fax)
✉INATTIC1@aol.com

NEO Fight
4363 Idlewild Ln.
Carmel, IN 46033-4716
(317) 255-5242
(317) 274-2846 (fax)
✉KMarrs@iupi.edu
http://member.tripod.com/~neofight

Project Special Care
4755 Kingsway Dr., Ste. 105
Indianapolis, IN 46205
(317) 257-8683
(317) 251-7488 (fax)

IOWA

Autism Society of the Quad Cities
PO Box 472
Bettendorf, IA 52722-0008
(319) 386-6359
(319) 359-5967 (fax)
✉gkarp@saunix.sau.edu

Area Education Agency 7
3712 Cedar Heights Dr.
Cedar Falls, IA 50613
(319) 273-8200
(319) 273-8291 (TTY)
(319) 273-8229 (fax)
✉dbergeson@aea7.k12.ia.us

The Arc of East Central Iowa Pilot Parents
214 First St. SW
Cedar Rapids, IA 52404
(800) 843-0272 (IA only)
(319) 365-0487
(319) 365-9936 (fax)

Tourette Syndrome
2101 O Ave. NW
Cedar Rapids, IA 52405
(319) 396-0210

Parent Educator Connection Program
Resource Center for Issues in Special Ed.
Drake University
2507 University Ave.
Des Moines, IA 50311-4505
(515) 271-3936
(515) 271-4185 (fax)
✉deb.samson@drake.edu

Area Education Agency (AEA) 5
1235 5th Ave. S.
Fort Dodge, IA 50501
(515) 574-5423
(515) 574-5508 (fax)
✉mshimkat@aea5.k12.ia.us
http://www.aea5.k12.ia.us

Tourette Syndrome Association of Iowa
307 S. 5th St.
Marshalltown, IA 50158
(515) 753-4157

Parent Educator Connection
Area Education Agency 4
1382 4th Ave. NE
Sioux Center, IA 51250
(800) 572-5073
(712) 772-4374
(712) 722-1643 (fax)
GMiller@aea4.k12.ia.us

KANSAS

Families Together/Parent to Parent of Kansas
501 Jackson, Ste. 400
Topeka, KS 66603
(800) 264-6343 (V/TTY, KS only)
(785) 233-4777 (V/TTY)
(785) 233-4787 (fax)
✉family@inlandnet.net

LOUISIANA

Families Helping Families of Greater New Orleans
4323 Division St., Ste. 110
Metairie, LA 70002-3179
(800) 766-7736 (LA only)
(504) 888-0246 (fax)
✉fhfgno@ix.netcom.com

Parent to Parent Programs

MAINE

Cumberland County Parent Awareness, Inc.
PO Box 6505
Portland, ME 04102
(207) 878-0523

Southern Maine Parent Awareness, Inc.
160 Main St., Midtown Mall
Sanford, ME 04073
(800) 564-9696 (ME Only)
(207) 324-2337
(207) 324-5621 (fax)
✉smpa@mmp.org

MARYLAND

Maryland Infant and Toddlers Program Family Support Network
Maryland State Dept. of Education
200 W. Baltimore, 4th Fl.
Baltimore, MD 21201
(410) 767-0652
(410) 333-8165 (fax)

National Organization of Parents of Blind Children
1800 Johnson St.
Baltimore, MD 21230
(410) 659-9314
(410) 685-5653 (fax)
✉nfb@iamdigex.net

Partners in Intensive Care, Inc
PO Box 41043
Bethesda, MD 20824-1043
(301) 681-2708
(202) 363-4659 (fax)

Epilepsy Foundation of America
4351 Garden City Dr.
Landover, MD 20785
(800) 332-1000
(800) 332-2070 (TTY)
(301) 577-2684 (fax)
✉postmaster@efa.org

The Arc Family Connection Parent to Parent Program
11600 Nebel St.
Rockville, MD 20852
(301) 984-5777
(301) 816-2429 (fax)

MASSACHUSETTS

Family Ties
Massachusetts Dept of Public Health
DCSHCN 4th Fl.
250 Washington St.
Boston, MA 02108
(800) 905-8437 (MA only)
(617) 624-5070
(617) 624-5075 (fax)
Division.CSHCN@state.ma.us

Federation for Children with Special Needs
1135 Tremont St.
Boston, MA 02120
(800) 331-0688 (MA only)
(617) 236-7210
(617) 572-2094 (fax)
✉fcsninfo@fcsn.org
http://www.fcsn.org

Greater Boston Assoc. for Citizens with Mental Retardation and Related Disabilities
1505 Commonwealth Ave.
Boston, MA 02135-3605
(617) 783-3900
(617) 783-9190 (fax)
✉bostonarc@aol.com

National Tay-Sachs and Allied Diseases Association
2001 Beacon St., Ste. 204
Boston, MA 02135
(800) 906-8723
(617) 277-4463
(617) 277-0134 (fax)
✉NTSD-boston@worldnet.att.net
http://www.ntasd.org

Massachusettes Down Syndrome Congress
PO Box 866
Melrose, MA 02176
(800) 664-6372 (MA only)
(617) 742-4440
(508) 278-4435 (fax)
http://www.mdsc.org

MICHIGAN

Family Support Network of MI Parent Participation Program-MDCH
200 6th St., 3rd Fl.
S. Tower, Ste. 316
Detroit, MI 48226-2495
(800) 359-3722
(800) 788-7889 (TTY)
(313) 256-2605 (fax)

MINNESOTA

Pilot Parents in Anoka and Ramsey Counties
1201 89th Ave. NE, Ste. 305
Blaine, MN 55434
(612) 783-4958
(612) 783-4900 (fax)

Arc Suburban
1526 E. 122nd St., E.
Burnsville, MN 55337
(612) 890-3057
(612) 890-3527 (fax)
✉arcsuburb@aol.com

Family Track Services or FAS/FAE or RESPITE Resources
Arc Northland
424 W. Superior St., Ste. 201
Duluth, MN 55802
(800) 317-6475
(218) 726-4732
(218) 726-4722 (fax)
✉arcdul@aol.com

Windmill Project
125 W. Lincoln Ave.
PO Box 54
Fergus Falls, MN 56537
(800) 257-5463
(218) 736-4982
(218) 739-3011
(218) 739-3727 (fax)
✉uwff@prtel.com

Family to Family Network
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For more information please contact:

Sandy A. Ross, MHS, PT, PCS
Senior Physical Therapist
Barnes-Jewish and St. Louis Children's Hospitals
Department of Rehabilitation at Washington University
4555 Forest Park Parkway
St. Louis, Missouri 63108

Phone: (314) 454-8335
Fax: (314) 454-5388
E-mail: sross@roadrunner.carenet.org
E-mail for the Human Performance Lab: roadrunner.carenet.org (grant summary and more information, click on "Subject Recruitment")

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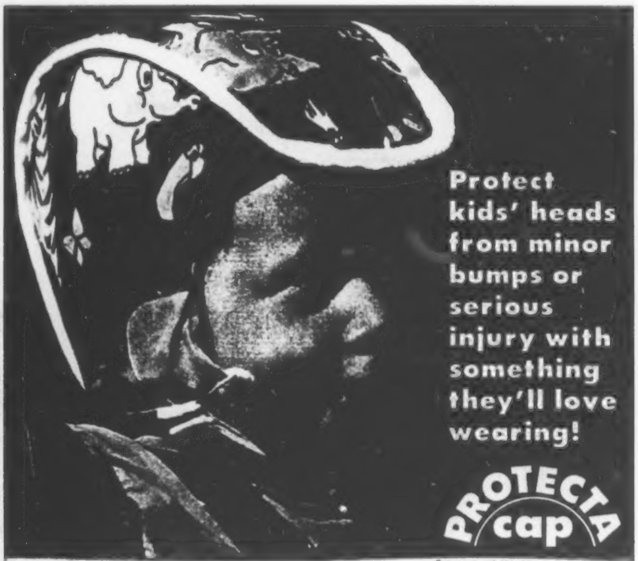
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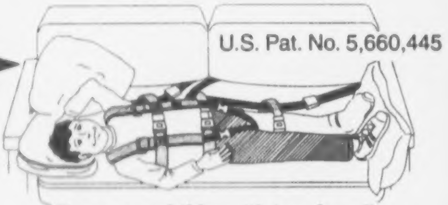

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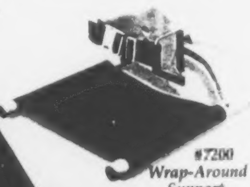
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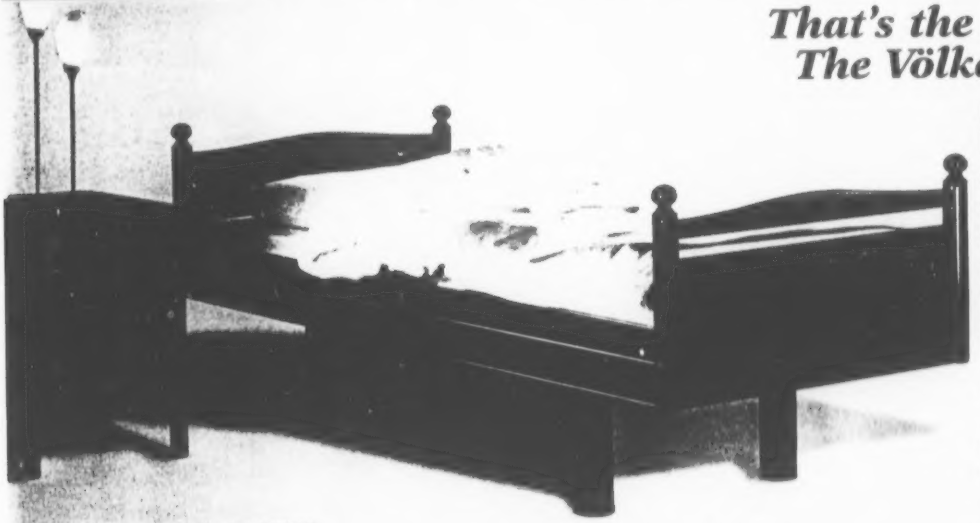

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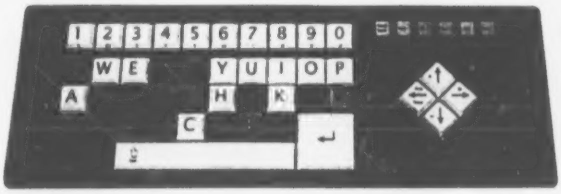

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The booklet "Dysphagia, A Review For Health Professionals" discusses causes, evaluation and treatment of dyspagia.

The pamphlet "Swallowing Problems" helps patients and caregivers understand and adapt to dysphagia.

BEST COPY AVAILABLE

Parent Training & Information Centers

Parent centers in each state provide training and information to parents of infants, toddlers, school-aged children, and young adults with disabilities and the professionals who work with their families. This assistance helps parents participate more effectively with professionals in meeting the educational needs of children and youth with disabilities. To reach the parent center in your state, you can contact **Alliance Coordinating Office:** PACER Center 4826 Chicago Ave. S.,Minneapolis, MN 55417-1098; (612) 827-2966 (888) 248-0822 (voice); (612) 827-7770 (TTY); (612) 827-3065 ((fax)); ✉alliance@taalliance.org; http://www.taalliance.org. The Technical Assistance Alliance for Parent Centers (the Alliance) coordinates the delivery of technical assistance to the Parent Training and Information Centers and the Community Parent Resource Centers through four regional centers.

Using this directory

When available, e-mail addresses and World Wide Web sites have been included. E-mail addresses are indicated by the ✉ symbol. Web sites are listed with standard **http://** before each. (Unless otherwise indicated, all telephone numbers are for voice only.)

(CPRC)=Community Parent Resource Center

Northeast Regional Center
Parent Information Center
P.O. Box 2405
Concord, NH 03302-2405
(603) 224-7005 voice
(603) 224-4379 (fax)
✉ipicnh@aol.com
CT, DE, DC, ME, MD, MA, NH, NJ, NY, PA, Puerto Rico, RI, US VI, VT

Midwest Regional Center
Ohio Coalition for the Education of Children with Disabilities (OCECD)
Bank One Building
165 West Center Street, Suite 302
Marion, OH 43302-3741
(740) 382-5452 voice
(740) 383-6421 (fax)
✉iocecd@gte.net
CO, IL, IA, IN, KS, KY, MI, MN, MO, NE, ND, OH, SD, WI

South Regional Center
Partners Resource Network, Inc.
1090 Longfellow Drive, Suite B
Beaumont, TX 77706-4819
(409) 898-4684 voice
(409) 898-4869 (fax)
✉txprn@pnx.com
AL, AR, FL, GA, LA, MS, NC, OK, SC, TN, TX, VA, WV

West Regional Center
Matrix Parent Network and Resource Center
94 Galli Drive, Suite C
Novato, CA 94949
(415) 884-3535
(415) 884-3555 (fax)
✉imatrix@matrixparents.org
AK, AZ, Department of Defense Dependent Schools (DODDS), CA, HI, ID, MT, NV, NM, OR, Pacific Jurisdiction, UT, WA, WY

ALABAMA

Special Education Action Committee Inc.
Carol Blades, Director
P.O. Box 161274
Mobile, AL 36616-2274
(334) 478-1208 (voice/TDD
(334) 473-7877 (fax
(800) 222-7322 AL only
✉seacofmobile@zebra.net
http://www.hsv.tis.net/~seachsv/

ALASKA

PARENTS, Inc.
Faye Nieto
4743 E. Northern Lights Blvd.
Anchorage, AK 99508
(907) 337-7678 Voice & TDD
(907) 337-7671 (fax)
(800) 478-7678 in AK
✉parents@alaska.net
http://www.alaska.net/~parents/

AMERICAN SAMOA

American Samoa PAVE
Fa' Anati Penitusi
P.O. Box 3432
Pago Pago, AS 96799
(011) 684-699-6946
(011) 684-699-6952 (fax)
✉SAMPAVE@samoatelco.com
http://www.taalliance.org/ptis/amsamoa/

ARIZONA

Pilot Parents of Southern Arizona
Lynn Kallis
2600 N Wyatt Dr
Tucson, AZ 85712
(520) 324-3150
(520) 324-3152 (fax)
✉PPSA@azstarnet.com
http://www.azstarnet.com/~ppsa

RAISING Special Kids
Marta Urbina
4750 N. Black Canyon Hwy, Ste 101
Phoenix, AZ 85017-3621
(602) 242-4366 (voice/TDD
(800) 237-3007 (AZ only)
(602) 242-4306 (fax)

ARKANSAS

Arkansas Disability Coalition
Wanda Stovall
1123 University Ave., Ste 225
Little Rock, AR 72204-1605
(501) 614-7020 (voice/TDD)(800) 223-1330 (AR only)
(501) 614-9082 (fax)
✉adc@alltel.net

FOCUS, Inc.
Ramona Hodges
305 West Jefferson Ave.
Jonesboro, AR 72401
(888) 247-3755
(870) 935-2750
(870) 931-3755 (fax)
✉focusinc@ipa.net

CALIFORNIA

DREDF
Diane Lipton
2212 Sixth St
Berkeley, CA 94710
(800) 466-4232
(510) 644-2555 (TDD available)
(510) 841-8645 (fax)
✉dredf@dredf.org
http://www.dredf.org

Exceptional Family Support, Education and Advocacy Center
Debbie Rowell
6402 Skyway
Paradise, CA 95969
(530) 876-8321
(530) 876-0346 (fax)
✉sea@sunset.net
http://www.sea-center.org

Exceptional Parents Unlimited
Leslie Lee
4120 N. First St.
Fresno, CA 93726
(559) 229-2000
(559) 229-2956 (fax)
✉epu1@cybergate.com

Loving Your Disabled Child (CPRC)
Theresa Cooper
4528 Crenshaw Blvd
Los Angeles, CA 90043
(323) 299-2925
(323) 299-4373 (fax)
✉lydc@pacbell.net

Matrix
Deidre Hayden
94 Galli Dr, Suite C
Novato, CA 94949
(415) 884-3535
(415) 884-3555 (fax)
(800) 578-2592
✉matrix@matrixparents.org
http://www.matrixparents.org

Parents Helping Parents of San Francisco
Lois Jones
594 Monterey Blvd.
San Francisco, CA 94127-2416
(415) 841-8820
(415) 841-8824 (fax)

Parents Helping Parents of Santa Clara
Mary Ellen Peterson
3041 Olcott St.
Santa Clara, CA 95054-3222
(408) 727-5775 Voice / (408) 727-7655 TDD
(408) 727-0182 (fax)
✉info@php.com
http://www.php.com

Support for Families of Children with Disabilities
Juno Duenas
2601 Mission #710
San Francisco, CA 94110-3111
(415) 282-7494
(415) 282-1226 (fax)
✉sfcdmiss@aol.com

TASK
Joan Tellefsen
100 West Cerritos Ave.
Anaheim, CA 92805
(714) 533-8275
(714) 533-2533 (fax)
✉taskca@aol.com

TASK, San Diego
Jesse Coronel, Director
3750 Convoy St., Suite 303
San Diego, CA 92111-3741
(619) 874-2386
(619) 874-2375 (fax)
✉tasksd1@aol.com

COLORADO

PEAK Parent Center, Inc.
Barbara Buswell/Judy Martz
6055 Lehman Drive, Suite 101
Colorado Springs, CO 80918
(800) 284-0251
(719) 531-9400
(719) 531-9403 (TDD)
(719) 531-9452 (fax)
✉info@peakparent.org
http://www.peakparent.org

CONNECTICUT

Connecticut Parent Advocacy Center
Nancy Prescott
338 Main Street
Niantic, CT. 06357
(800) 445-2722 (CT only)
(860) 739-3089 (voice/TDD)
(860) 739-7460 (fax) (Call first to dedicate line)
✉cpacinc@aol.com
http://members.aol.com/cpacinc/cpac.htm

DELAWARE

Parent Information Center (PIC)
Marie-Anne Aghazadian
700 Barksdale Road, Suite 3
Newark, DE 19711
(302) 366-0152 voice
(302) 366-0178 (TDD)
(302) 366-0276 (fax)
✉picofdel@picofdel.org
http://www.picofdel.org

DISTRICT OF COLUMBIA

Advocates for Justice and Education
Bethann West
2041 Martin Luther King Ave., SE, Suite 301
Washington, DC 20020
(888) 327-8060
(202) 678-8060
(202) 678-8062 (fax)
✉justice1@bellatlantic.net
http://www.aje.qpg.com/
District of Columbia

FLORIDA

Family Network on Disabilities
Jan LaBelle
2735 Whitney Road
Clearwater, FL 33760-1610
(800) 825-5736 (FL only)
(727) 523-1130
(727) 523-8687 (fax)
✉fnd@fndfl.org
http://fndfl.org

Parent to Parent of Miami, Inc. (CPRC)
Janet Bell Taylor
c/o Sunrise Community
9040 Sunset Drive, Suite G
Miami, FL 33173
(305) 271-9797
(305) 271-6628 (fax)
✉PtoP1086@aol.com

GEORGIA

Parents Educating Parents and Professionals for All Children (PEPPAC)
Linda Shepard
6613 East Church Street, Suite 100
Douglasville, GA 30134
(770) 577-7771
(770) 577-7774 (fax)
peppac@bellsouth.net
http://www.peppac.org

HAWAII

AWARE
Jennifer Schember-Lang, Exec Director
200 N. Vineyard Blvd., Suite 310
Honolulu, HI 96817
(808) 536-9684
(808) 536-2280 (voice & TTY
(808) 537-6780 (fax)
✉ldah@gte.net

Palau Parent Network
Jennifer Schember-Lang, Exec Director
200 N. Vineyard Blvd., Suite 310
Honolulu, HI 96817
(808) 536-9684
(808) 536-2280 (voice/TTY)
(808) 537-6780 (fax)
✉ldah@gte.net

IDAHO

Idaho Parents Unlimited, Inc.
Cheryl Fisher
4696 Overland Road, Suite 568
Boise, ID 83705
(800) 242-4785
(208) 342-5884 (voice/TDD
(208) 342-1408 (fax)
✉ipul@rmci.net
home.rmci.net/ipul

Native American Parent Training and Information Center
Chris Curry & Susan Banks
129 East Third
Moscow, ID 83843
(208) 885-3500
famtog@moscow.com
Nation-wide resource for Native American families, tribes, and communities as well as parent centers and others needing information on this subject.

ILLINOIS

Designs for Change
Donald Moore/Miguel Jimanez
6 North Michigan Ave., Suite 1600
Chicago, IL 60602
(800) 851-8728
(312) 857-9292
(312) 857-1013 (TDD)
(312) 857-9299 (fax)
✉dfc1@aol.com

Family Resource Center on Disabilities
Charlotte Des Jardins
20 E. Jackson Blvd., Rm. 300
Chicago, IL 60604
(800) 952-4199 (IL only)
(312) 939-3513 voice
(312) 939-3519 (TTY & TDY)
(312) 939-7297 (fax)
✉frcdptiil@ameritech.net
http://www.ameritech.net/users/frcdptiil/index.html

Family T.I.E.S. Network
Deb Kunz
830 South Spring
Springfield, IL 62704
(800) 865-7842
(217) 544-5809
(217) 544-6018 (fax)
✉ftiesn@aol.com
http://www.taalliance.org/ptis/fties/

National Center for Latinos with Disabilities
Maria Elena Rodriguez-Sullivan
1921 South Blue Island Ave.
Chicago, IL 60608
(800) 532-3393
(312) 666-3393
(312) 666-1788 (TTY)
(312) 666-1787 (fax)
✉ncld@ncld.com
homepage.interaccess.com/~ncld/

INDIANA

IN*SOURCE
Richard Burden
809 N. Michigan St.
South Bend, IN 46601-1036
(800) 332-4433 (IN only)
(219) 234-7101
(219) 239-7275 (TDD)
(219) 234-7279 (fax)
✉insourc1@aol.com
http://www.insource.org

IOWA

Access for Special Kids (ASK)
Jule Reynolds
321 E. 6th St
Des Moines, IA 50309
(800) 450-8667
(515) 243-1713
(515) 243-1902 (fax)
✉ptiiowa@aol.com
http://www.taalliance.org/ptis/ia/

KANSAS

Families ACT (CPRC)
Nina Lomely-Baker
1403 Perry
Wichita, KS 57203
(316) 685-1821
(316) 685-0768 (fax)
mha@southwind.net
www.mhasck.org
Sedgwick County and Outlying area

Families Together, Inc.
Connie Zienkewicz
3340 W Douglas, Ste 102
Wichita, KS 67203
(888) 815-6364
(316) 945-7747
(316) 945-7795 (fax)
✉fmin@feist.com
http://www.kansas.net/~family/

KENTUCKY

Family Training & Information Center
Paulette Logsdon
2210 Goldsmith Lane, Suite 118
Louisville, KY 40218
(800) 525-7746
(502) 456-0923
(502) 456-0893 (fax)
✉spininc@aol.com

LOUISIANA

Pyramid Parent Training Program (CPRC)
Ursula Markey
4101 Fontainbleau Dr
New Orleans, LA 70125
(504) 827-0610
(504) 827-2999 (fax)
✉dmarkey404@aol.com

Project PROMPT
Leah Knight
4323 Division Street, Suite 110
Metairie, LA 70002-3179
(800) 766-7736
(504) 888-9111
(504) 888-0246 (fax)
✉fhfgno@ix.netcom.com
http://www.projectprompt.com

MAINE

Special Needs Parent Info Network
Janice LaChance
P.O. Box 2067
Augusta, ME 04338-2067
(800) 870-SPIN (7746) (ME only)
(207) 582-2504
(207) 582-3638 (fax)
✉jlachance@mpf.org
http://www.mpf.org

MARYLAND

Parents Place of Maryland, Inc.
Josie Thomas
7484 Candlewood Rd Suite S
Hanover, MD 21076-1306
(410) 859-5300 (voice/TDD)
(410) 859-5301 (fax)
✉info@ppmd.org
http://www.ppmd.org

MASSACHUSETTS

Federation for Children with Special Needs
Richard Robison
1135 Tremont Street, Suite 420
Boston, MA 02120-2140
(800) 331-0688 (MA only)
(617) 236-7210 (voice/ TTY)
(617) 572-2094 (fax)
✉fcsninfo@fcsn.org
http://www.fcsn.org/

MICHIGAN

CAUSE
Patrick Strong
3303 W. Saginaw, Suite F-1
Lansing, MI 48917-2303
(800) 221-9105 (MI only)
(517) 886-9167 (voice/TDD /TDY)
(517) 886-9775 (fax)
✉info-cause@voyager.net
http://www.pathwaynet.com/cause/

Parents are Experts
Pat Dwelle
23077 Greenfield Road, Suite 205
Southfield, MI 48075-3745
(800) 827-4843
(248) 557-5070 (voice/TDD
(248) 557-4456 (fax)
✉ucp@ameritech.net
http://www.taalliance.org/ptis/mi-parents/

MINNESOTA

PACER Center, Inc.
Paula Goloberg/Virginia Richardson
4826 Chicago Avenue South
Minneapolis, MN 55417-1098
(800) 537-2237 (MN only)
(612) 827-2966
(612) 827-7770 (TTY)
(612) 827-3065 (fax)
✉pacer@pacer.org
http://www.pacer.org

MISSISSIPPI

Parent Partners
Aretha Lee, Director
1900 North West St, Ste. C-100
Jackson, MS 39202
(800) 366-5707 (MS only)
(601) 714-5707
(601) 714-4025 (fax)
✉ptiofms@misnet.com
http://www.taalliance.org/ptis/ms/

Project Empower (CPRC)
Agnes Johnson
136 South Poplar Ave
Greenville, MS 38701
(800) 337-4852
(601) 332-4852
(601) 332-1622 (fax)
✉empower@tecinfo.com

MISSOURI

Missouri Parents Act
Sonia Moran
2100 S. Brentwood, Suite G
Springfield, MO 65804
(800) 743-7634 (MO only)
(417) 882-7434
(417) 882-8413 (fax)
✉mpactsm@axs.net
http://www.cm.org/mpact/

MPACT - Kansas City Metro
1 West Armour Blvd, Suite 301
Kansas City, MO 64111-2087
(877) 588-5644
(816) 531-7070
(816) 531-4777 (fax)
✉mpacts@cm.org

MPACT - North
601 West Main
Savannah, MO 64485-1614
(877) 384-2989
(816) 324-7046
✉mpactps@ponyexpress.net

MPACT - St. Louis Metro
4144 Lindell Blvd., Siute 405
St. Louis, MO 63108-2964
(800) 995-3160
(314) 531-5822
(314) 531-8138 (fax)
✉mpactstl@socket.net

MPACT - Southwest
2100 South Brentwood, Suite G
Springfield, MO 65804-2534
(800) 743-7634
(417) 882-7434
(417) 882-8413 (fax)
✉mpactspr@axs.net

MPACT - Southeast
RR 2, Box 2530
Sedgewickville, MO 63781-9705
(877) 876-2831
(573) 866-3292 (fax)
Administrative Assistant
3560 Highway A
Bland, MO 65014
(573) 646-5275 Phone & (fax)
✉bierempact@socket.net

MONTANA

Parents Let's Unite for Kids
Katharin Kelker
516 N. 32nd Street
Billings, MT 59101
(800) 222-7585 (MT only)
(406) 255-0540
(406) 255-0523 (fax)
✉plukinfo@pluk.org
http://www.pluk.org

NEBRASKA

Nebraska Parents Center
Glenda Davis
1941 South 42nd St., #122
Omaha, NE 68105-2942
(800) 284-8520
(402) 346-0525 (voice/TDD
(402) 346-5253 (fax)
✉gdavis@neparentcenter.org
http://www.neparentcenter.org

NEVADA

Nevada Parents Encouraging Parents (PEP)
Karen Taycher
2810 W. Charleston Blvd.,
Suite G-68
Quail Park IV
Las Vegas, NV 89102
(800) 216-5188
(702) 388-8899
(702) 388-2966 (fax)
✉nvpep@vegas.infi.net
mh102.infi.net/~nvpep/

NEW HAMPSHIRE

Parent Information Center
Judith Raskin
P.O. Box 2405
Concord, NH 03302-2405
(800) 232-0986 (NH only)
(603) 224-7005 (voice/TDD)
(603) 224-4379 (fax)
picnh@aol.com
http://www.taalliance.org/ptis/nhpic/

NEW JERSEY

Statewide Parent Advocacy Network (SPAN)
Diana MTK Audn
35 Halsey Street, 4th Floor
Newark, NJ 07102
(800) 654-SPAN (7726)
(973) 642-8100
(973) 642-8080 (fax)
✉span@bellatlantic.net
http://www.taalliance.org/ptis/nj/

NEW MEXICO

Parents Reaching Out, Project ADOBE
Larry Fuller
1000-A Main St. NW
Los Lunas, NM 87031
(800) 524-5176 (NM only)
(505) 865-3700 (voice/TDD
(505) 865-3737 (fax)
✉nmproth@aol.com
http://www.parentsreachingout.org

NEW YORK

The Advocacy Center
Colin Garwood
277 Alexander St., Suite 500
Rochester, NY 14607
(800) 650-4967 (NY only)
(716) 546-1700
(716) 546-7069 (fax)
advocacy@frontiernet.net
http://www.advocacycenter.com

Advocates for Children of NY
Ana Espada
151 West 50th Street, 5th Floor
Brooklyn, NY 10001
(212) 947-9779
(212) 947-9790 (fax)
✉info@advocatesforchildren.org
http://www.advocatesforchildren.org

Resources for Children with Special Needs
Karen Schlesinger, Director
200 Park Ave. S., Suite 816
New York, NY 10003
(212) 677-4650
(212) 254-4070 (fax)
resourcesnyc@prodigy.net

Parent Training & Information Centers

Sinergia/Metropolitan Parent Center
Donald Lash, Executive Director
15 West 65th St., 6th Floor
New York, NY 10023
(212) 496-1300
(212) 496-5608 (fax)
✉Sinergia@panix.com
http://www.panix.com/~sinergia/

United We Stand (CPRC)
Lourdes Rivera-Putz
c/o Casa del Barrio
728 Driggs Ave
Brooklyn, NY 11211
(718) 302-4313, ext. 562
(718) 302-4315 (fax)
uwsofny@aol.com
http://www.taalliance.org/ptis/uws/

NORTH CAROLINA

ECAC, Inc.
Connie Hawkins
PO Box 16
Davidson, NC 28036
(800) 962-6817 (NC only)
(704) 892-1321
(704) 892-5028 (fax) (Call first to dedicate line)
✉ECAC1@aol.com

NORTH DAKOTA

Pathfinder Family Center
Kathryn Erickson
Arrowhead Shopping Center
1600 2nd Ave. SW
Minot, ND 58701
(800) 245-5840 (ND only)
(701) 837-7500
(701) 837-7501 (TTY)
(701) 837-7548 (fax)
✉ndpath01@minot.ndak.net
pathfinder.minot.com

OHIO

Child Advocacy Center
Cathy Heizman
1821 Summit Road, Suite 303
Cincinnati, OH 45237
(513) 821-2400
(513) 821-2442 (fax)
✉CADCenter@aol.com

OCECD
Margaret Burley
Bank One Building
165 West Center St., Suite 302
Marion, OH 43302-3741
(800) 374-2806
(740) 382-5452 (voice & TDD)
(740) 383-6421 (fax)
✉ocecd@gte.net
http://www.taalliance.org/PTIs/regohio/

OKLAHOMA

Parents Reaching Out in OK
Sharon Bishop
1917 S. Harvard Avenue
Oklahoma City, OK 73128
(800) PL94-142
(405) 681-9710
(405) 685-4006 (fax)
✉prook1@aol.com
http://www.taalliance.org/ptis/ok/

OREGON

Oregon COPE Project
Anne Brown
999 Locust St. NE
Salem, OR 97303
(888) 505-COPE (2673)
(503) 581-8156 (voice/TDD)
(503) 391-0429 (fax)
✉orcope@open.org
http://www.open.org/~orcope

PENNSYLVANIA

Hispanos Unidas para Vinos Impedidos
(Hispanics United for Special Needs Children)
Liz Hernandez
149 W Susquehanna Ave
Philadelphia, PA 19122
(215) 425-6203
(215) 425-6204 (fax)
✉ParentsU@aol.com

Parent Education Network
Louise Thieme
2107 Industrial Hwy
York, PA 17402-2223
(800) 522-5827 (PA only)
(800) 441-5028 (Spanish in PA)
(717) 600-0100 (voice/TTY)
(717) 600-1801 (fax)
✉pen@parentednet.org
http://www.parentednet.org

Parents Union for Public Schools
Janet Lonsdale
311 S. Juniper St., Suite 200
Philadelphia, PA 19107
(215) 546-1166
(215) 731-1688 (fax)
✉ParentsU@aol.com

PUERTO RICO

APNI
Carmen Sellés deVita
P.O. Box 21301
Ponce de Leon 724
San Juan, PR 00928-1301
(800) 981-8492
(800) 949-4232
(787) 250-4552
(787) 765-0345 (fax)
✉apnipr@prtc.net
Island of Puerto Rico

RHODE ISLAND

RI Parent Information Network
Cheryl Collins
175 Main Street
Pawtucket, RI 02860
(800) 464-3399 (RI only)
(401) 727-4144
(401) 727-4151 (TDD)
(401) 727-4040 (fax)
✉collins@ripin.org
http://www.ripin.org/

SOUTH CAROLINA

Advocacy Coalition for Youth with Disabilities
Beverly McCarty
c/o Family Resource Center
135 Rutledge Ave.
PO Box 250567
Charleston, SC 29425
(843) 876-1519
(843) 876-1518 (fax)
✉mccartyb@musc.edu

PRO-PARENTS
Mary Eaddy
2712 Middleburg Drive, Suite 203
Columbia, SC 29204
(800) 759-4776 (SC only)
(803) 779-3859 (voice/TDD)
(803) 252-4513 (fax)
✉pro-parents@aol.com

SOUTH DAKOTA

South Dakota Parent Connection
Bev Petersen
3701 West 49th St., Suite 200B
Sioux Falls, SD 57106
(800) 640-4553 (SD only)
(605) 361-3171 (voice/TDD)
(605) 361-2928 (fax)
✉bpete@dakota.net
http://www.sdparent.org

TENNESSEE

Support and Training for Exceptional Parents, Inc. (STEP)
Nancy Diehl
424 E. Bernard Ave., Suite 3
Greeneville, TN 37745
(800) 280-STEP (7837) (TN only)
(423) 639-0125
(636) 8217 (TDD)
(423) 636-8217 (fax)
✉tnstep@aol.com
http://www.tnstep.org

TEXAS

El Valle Community Parent Resource Center (CPRC)
Laura Reagan
530 South Texas Blvd, Ste. J
Weslaco, TX 78596
(800) 680-0255 (TX only)
(956) 969-3611
(956) 969-8761 (fax)
✉lmdr2@aol.com
http://www.tfepoder.org

Grassroots Consortium
Agnes A. Johnson
6202 Belmark
PO Box 61628
Houston, TX 77087
(713) 643-9576
(713) 643-6291 (fax)
speckids@pdq.net
Comprised of various community groups nationwide

Parents Supporting Parents Network (CPRC)
David Meraz
601 N Texas Blvd, Suite C
Weslaco, TX 78596
(956) 447-8408
(956) 973-9503 (fax)
✉weslaco@gte.net

Partners Resource Network Inc.
Janice Meyer
1090 Longfellow Drive, Suite B
Beaumont, TX 77706-4819
(800) 866-4726 (TX only)
(409) 898-4684 Voice & TDD
(409) 898-4869 (fax)
✉txprn@pnx.com
http://www.PartnersTX.org

Project PODER
Yvette Hinojosa
1017 N. Main Ave., Suite 207
San Antonio, TX 78212
(800) 682-9747 (TX only)
(210) 222-2637
(210) 475-9283 (fax)
✉poder@tfepoder.org
http://www.tfepoder.org

UTAH

Utah Parent Center
Helen Post
2290 East 4500 S., Suite 110
Salt Lake City, UT 84117
(800) 468-1160 (UT only)
(801) 272-1051
(801) 272-8907 (fax)
✉upc@inconnect.com
http://www.utahparentcenter.org

VERMONT

Vermont Parent Information Center
Connie Curtin
1 Mill Street, Suite A7
Burlington, VT 05401
(800) 639-7170 (VT only)
(802) 658-5315 (voice/TDD
(802) 658-5395 (fax)
✉vpic@together.net
homepages.together.net/~vpic

VIRGIN ISLANDS

V.I. FIND
Catherine Rehema Glenn
#2 Nye Gade
St. Thomas, US VI 00802
(340) 774-1662
(340) 775-3962 (fax)
✉vifind@islands.vi
http://www.taalliance.org/ptis/vifind/
Virgin Islands

VIRGINIA

PADDA, Inc. (CPRC)
Mark Jacob
813 Forrest Drive, Suite 3
Newport News, VA 23606
(888) 337-2332
(757) 591-9119
(757) 591-8990 (fax)
webmaster@padda.org
http://www.padda.org

Parent Educational Advocacy Training Center
Cheri Takemoto
6320 Augusta Drive
Springfield, VA 22150
(800) 869-6782 (VA only)
(703) 923-0010
(703) 923-0030 (fax)
partners@peatc.org
http://www.peatc.org

WASHINGTON

Parent to Parent Power (CPRC)
1118 S 142nd St.
Tacoma, WA 98444
(253) 531-2022
(253) 538-1126 (fax)
✉ylink@aa.net

PAVE/STOMP
Heather Hebdon
6316 South 12th St.
Tacoma, WA 98465
(800) 572-7368
(253) 565-2266 (voice/TTY)
(253) 566-8052 (fax)
✉wapave9@washingtonpave.org
washingtonpave.org/stomp.html

U.S. Military installations; and as a resource for parent centers and others needing information on this subject.

Washington PAVE
Joanne Butts
6316 South 12th
Tacoma, WA 98465-1900
(800) 572-7368 (WA only)
(253) 565-2266 (voice/TDD)
(253) 566-8052 (fax)
✉wapave9@washingtonpave.org
washingtonpave.org

WEST VIRGINIA

West Virginia PTI
Pat Haberbosch
371 Broaddus Ave
Clarksburg, WV 26301
(800) 281-1436 (WV only)
(304) 624-1436 (voice/TTY)
(304) 624-1438
✉wvpti@aol.com
http://www.taalliance.org/ptis/wv/

WISCONSIN

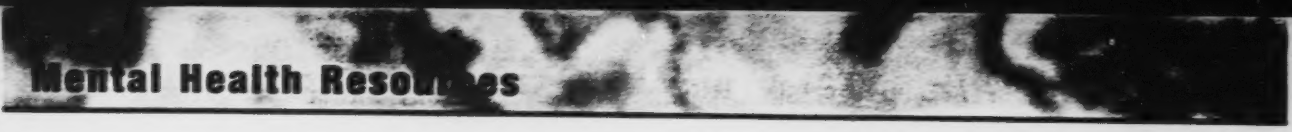
Native American Family Empowerment Center
Don Rosin
Great Lakes Inter-Tribal Council, Inc.
2932 Highway 47N, P.O. Box 9
Lac du Flambeau, WI 54538
(800) 472-7207 (WI only)
(715) 588-3324
(715) 588-7900 (fax)
✉drosin@newnorth.net

Parent Education Project of Wisconsin
S. Patrice Colletti, SDS
2192 South 60th Street
West Allis, WI 53219-1568
(800) 231-8382 (WI only)
(414) 328-5520
(414) 328-5525 (TDD)
(414) 328-5530
✉PMColletti@aol.com
members.aol.com/pepofwi/

Wisconsin Family Assistance Center for Education, Training and Support (CPRC)
Janis M. Serak
2714 North Dr. Martin Luther King Dr., Suite E
Milwaukee, WI 53212
(414) 374-4645 /
414-374-4635 (TTD)
(414) 374-4655 (fax)
✉wifacets@execpc.com

WYOMING

Parent Information Center
Terri Dawson
5 North Lobban
Buffalo, WY 82834
(800) 660-9742 (WY only)
(307) 684-2277 (voice/TDD)
(307) 684-5314
✉tdawsonpic@vcn.com
http://www.wpic.org



Mental Health Resources

Special help is available, in some states, for families with children and adolescents, who have serious emotional disturbances, through projects funded by the Center for Mental Health Services within the Federal Substance Abuse and Mental Health Services Administration. These projects were created with the vision of providing services for individuals through "systems of care:" community-based, comprehensive, coordinated, flexible, family-centered, and culturally competent.

These support projects are designed to help family-controlled, not-for-profit, private-sector organizations build and maintain networks of family members and others who are responsible for services to children and adolescents with serious emotional disturbances as well as their families. The projects assist individual families through information, referrals, and other support. In addition, they educate service providers, policy makers, and other interested parties about the needs of these children, adolescents, and families.

This directory includes the addresses and phone numbers of these projects. When available, World Wide Web sites and e-mail addresses have been included. Web sites are listed with the the standard **http://** before each. E-mail addresses are indicated by the symbol, ✉. (Unless otherwise indicated, all telephone numbers are for voice only.)

CALIFORNIA

United Advocates for Children of California (UACC)
PO Box 8900
Emeryville, CA 94662-8900
(510) 547-8754 (voice/fax)
✉uacc@pacbell.net

COLORADO

Mental Health Association of Colorado
6795 E Tennessee Ave., Ste. 425
Denver, CO 80224
(303) 377-3040
(303) 377-4920 (fax)

CONNECTICUT

The Connecticut Federation of Families for Children's Mental Health
282 Washington St.
Hartford, CT 06106
(860) 545-9057
(860) 545-9201 (fax)
✉danders@ccmckids.org

DISTRICT OF COLUMBIA

Family Advocacy & Support Association
3700 10th St. NW
Washington, DC 20010
(202) 576-6065
(202) 576-8804 (fax)

FLORIDA

Family Network on Disabilities of Florida
2735 Whitney Rd.
Clearwater, FL 33760
(800) 825-5736 (FL only)
(727) 523-1130
(727) 523-8687 (fax)
http://www.fndfl.org
✉fnd@gate.net

GEORGIA

Georgia Parent Support Network, Inc.
620 Peachtree St. NE
Atlanta, GA 30308
(800) 832-8645
(404) 875-6801
(404) 875-6755 (fax)
✉gpsn@mindspring.com

HAWAII

Hawaii Families as Allies
200 N. Vineyard Blvd.,
Ste. 300
Honolulu, HI 96817
(808) 521-1846
(808) 533-6995 (fax)

ILLINOIS

Illinois Federation of Families
800 W. Roosevelt Rd.,
Bldg. D-107
Glen Ellyn, IL 60137
(800) 871-8400
(630) 858-1849 (fax)
✉iffed@flashnet.com

KANSAS

Keys for Networking, Inc. State of Kansas Federation of Families for Children's Mental Health
117 SW 6th Ave.
Topeka, KS 66603
(800) 499-8752 (KS only)
(913) 233-8732
(913) 235-6659 (fax)
✉jadams@keys.org

KENTUCKY

KY-SPIN, Inc.
2210 Goldsmith Ln., Ste. 18
Louisville, KY 40218
(800) 525-7746
(502) 456-0923
(502) 456-0893 (fax)

LOUISIANA

Louisiana Federation of Families for Children's Mental Health
PO Box 4767
Shreveport, LA 71134-0767
(800) 224-4010
(318) 227-2796
(318) 227-2793 (fax)
✉lafofcmh@aol.com

MICHIGAN

Michigan Association for Children with Emotional Disorders
15920 W. Twelve Mile Rd., Ste. 201
Southfield, MI 48076
(242) 552-0044
(248) 522-0047 (fax)

Association for Children's Mental Health
941 Abbott Rd.
East Lansing, MI 48823
(517) 336-7222
(800) 782-0883 (parent line)
(517) 336-8884 (fax)
✉acmhinc@aol.com

MISSISSIPPI

Mississippi Families as Allies, Inc.
5166 Keele St., Ste. B-100
Jackson, MS 39206
(800) 833-9671
(601) 981-1618
(601) 981-1696 (fax)

MISSOURI

MO-Span (Missouri Statewide Parent Advisory Network)
580 S. Castello
Florissant, MO 63031
(314) 972-0600
(314) 972-0606 (fax)

MINNESOTA

Pacer Center, Inc.
4826 Chicago Ave. S.
Minneapolis, MN 55417-1098
(800) 537-2237 (MN only)
(612) 827-2966
(612) 827-7770 (TTY)
(612) 827-3065 (fax)
http://www.pacer.org
✉pacer@pacer.org

MONTANA

Family Support Network
PO Box 21366
Billings, MT 59104
(877) 376-4850
(406) 256-7783
(406) 256-9879 (fax)

NEW YORK

Families Together in NY State, Inc.
PO Box 8630
405 Quail St.
Albany, NY 12208
(888) 326-8644 (NY only)
(518) 459-5887
(518) 459-5883 (fax)
✉famstrong@albany.net

NORTH CAROLINA

Families CAN (Children and Adolescents Network)
3820 Merton Dr., Ste. 216
Raleigh, NC 27607
(800) 211-0501
(919) 785-1882
(919) 785-1533 (fax)
✉LMBLC8@aol.com

OREGON

Oregon Family Support Network
PO Box 13820
Salem, OR 97309-1820
(800) 323-8521 (OR only)
(503) 581-2047
(503) 581-4841 (fax)
✉ofsn@open.org

RHODE ISLAND

Parent Support Network of Rhode Island
250 Centerville Rd., Bldg. F
Warwick, RI 02886
(800) 483-8844 (RI only)
(401) 736-8844
(401) 736-8584 (fax)

TENNESSEE

Tennessee Voices for Children
2200 21st Ave. S.
Ste. 302
Nashville, TN 37212
(800) 670-9882
(615) 269-7751
(615) 269-8914 (fax)
http://www.mindspring.com/~tvc
✉tvc@mindspring.com

TEXAS

The Parent Connection
1020 Riverwood Ct.
Conroe, TX 77304
(800) 839-8876
(409) 756-8321
(409) 756-8326 (fax)

UTAH

Utah Parent Center
2290 E. 4500 S., Ste. 110
Salt Lake City, UT 84117
(800) 468-1160 (UT only)
(801) 272-1051
(801) 272-8907 (fax)
✉upc@inconnect.com

VERMONT

Vermont Federation of Families for Children's Mental Health
PO Box 607
Montpelier, VT 05601-0607
(802) 223-4917
(802) 828-2159 (fax)
✉vffcmh@together.net

VIRGINIA

Parents & Children Coping Together-PACCT
PO Box 26691
Richmond, VA 23261-6691
(800) 788-0097
(804) 559-6833
(804) 559-6835 (fax)
✉pacct@richmond.infi.net

WISCONSIN

Wisconsin Family Ties
16 N. Carroll St., Ste. 640
Madison, WI 53703
(800) 422-7145
(608) 267-6888
(608) 267-6801 (fax)
http://www.wifamilyties.org
✉info@wifamilyties.org

WYOMING

Uplift
PO Box 664
Cheyenne, WY 82003
(307) 778-8686
(307) 322-4561 (fax)
✉uplift@coffey.com

BEST COPY AVAILABLE

University Affiliated Programs

Authorized by Federal legislation to help states and local communities respond to the needs of people with developmental disabilities and their families, University Affiliated Programs (UAPs) serve as a liaison between the academic world and the developmental disabilities service delivery system. UAPs network with and provide assistance to State Agencies, their local affiliates, and to various nongovernmental consumer-based organizations.

Most UAPs provide direct clinical, educational, and other services to individuals and families, or can assist families in finding services. UAP Mental Retardation/Developmental Disabilities Research Centers, indicated by an (R) following the center name, are also included in this directory even though they may not provide direct services. These centers develop essential knowledge and information upon which to base new and improved treatments, supports, and services. Some of these research centers are housed at the same academic settings as the UAPs providing direct services.

These listings were provided by the American Association of University Affiliated Programs for Persons with Developmental Disabilities, 8630 Fenton St., Ste. 410, Silver Spring, MD 20910; telephone: (301) 588-8252 (voice); (301) 588-3319 (TDD);
fax: (301) 588-2842. Web site: http://www.aauap.org

Using This Directory
When available, World Wide Web sites and e-mail addresses have been included. Web sites are listed with the standard **http://** before each. (Unless otherwise indicated, all telephone numbers are for voice only.)

ALASKA

University of Alaska Anchorage
Center for Human Development: UAP
Anchorage, AK 99508
(907) 272-8270
(907) 274-4802 (fax)
http://www.uaa.alaska.edu/uap/

ALABAMA

University of Alabama at Birmingham
Civitan International Research Center
Birmingham, AL 35294-0021
(205) 934-8900
(205) 975-6330 (fax)
http://www.circ.uab.edu/

ARIZONA

Northern Arizona UAP
Institute for Human Development
Flagstaff, AZ 86011-5630
(520) 523-4791 (520) 523-9127 (fax)
http://www.nau.edu/~ihd/

ARKANSAS

University of Arkansas
University Affiliated Program
501 Woodlane, Ste. 201
Little Rock, AR 72201
(501) 682-9900 (501) 682-9901 (fax)
http://www.uams.edu/uap

CALIFORNIA

University of California at Los Angeles
Mental Retardation and Developmental Disabilities Program
300 UCLA Medical Plaza, Ste 3302
Los Angeles, CA 90095-6967
(310) 825-0171 (310) 825-0170 (fax)

Children's Hospital Los Angeles
University Affiliated Training Program
450 Sunset Blvd
Los Angeles, CA 90027
(323) 669-2300 (323) 953-0439 (fax)
http://www.usc.edu/go/uap

COLORADO

University of Colorado Health Science Center
JFK Partners
4200 East 9th Avenue, Box C221
Denver, CO 80262
(303) 864-5261
03) 864-5270 (fax)
://www.uchsc.edu/sm/jfk/

CONNECTICUT

A.J. Pappanikou Center on Special Education and Rehabilitation
249 Glenbrook Rd, U-64
Storrs, CT 06269-2064
(860)486-5035
(860) 486-5037 (fax)
http://www.ucc.uconn.edu/~wwwpcse

DISTICT OF COLUMBIA

Georgetown University
Child Development Center
3307 M Street NW, Ste. 401
Washington, DC 20007-3935
(202) 687-8635
(202) 687-1954 (fax)
http://www.dml.georgetown.edu/depts/pediatrics/gucdc

DELWARE

University of Delaware
Center for Disabilities Studies
101 Alison Hall, Academy St.
Newark, DE 19716-7355
(302) 831-6974
(302) 831-4690 (fax)
http://www.udel.edu/chep/cds

FLORIDA

University of Miami School of Medicine
Mailman Center for Child Development
Miami, FL 33136
(305) 243-6801
(305) 243-5978 (fax)
http://pediatrics.med.miami.edu

GEORGIA

Institute on Human Development and Disability
A University Affiliated Program
850 College Station Road
Athens, GA 30602-3622
(706) 542-3457
(706) 542-4815 (fax)
http://www.uap.uga.edu

GUAM

University of Guam UAP
College of Education
Mangilao, GU 96923
(671) 735-2481
(671) 734-5709 (fax)

HAWAII

University of Hawaii at Manoa UAP
Center on Disability Studies
1776 University Ave, UA4-6
Honolulu, HI 96822
(808) 956-5011
(808) 956-7878 (fax)
http://www.cds.hawaii.edu/

Pacific Basin University Affiliated Program
University of Hawaii at Manoa
Honolulu, HI 96822
(808) 956-5009
(808) 956-7878 (fax)
http://www.cds.hawaii.edu

IOWA

University of Iowa UAP
University Hospital School
100 Hawkins Drive, Rm 2471R
Iowa City, IA 52242-1011
(319) 356-1335
(319) 356-8284 (fax)
http://www.medicine.uiowa.edu/uhs

IDAHO

University of Idaho UAP
Center on Disabilities and Human Development (CDHD)
129 West Third Street
Moscow, ID 83843
(208) 885-3559
(208) 885-3628 (fax)
http://www.ets.uidaho.edu/cdhd/

ILLINOIS

University of Illinois UAP
Institute on Disability & Human Development
Chicago, IL 60608
(312) 413-1647 .
(312) 413-1326 (fax)
http://www.uic.edu/depts/idhd

INDIANA

Indiana Institute on Disability and Community
The University Affiliated Program of Indiana
Indiana University, Bloomington
2853 E 10th Street
Bloomington, IN 47408-2696
(812) 855-6508
(812) 855-9630 (fax)
http://www.iidc.indiana.edu/

Riley Child Development Center
702 Barnhill Drive, Rm 5837
Indianapolis, IN 46202-5225
(317) 274-8167
(317) 274-9760 (fax)
http://www.child-dev.com

KANSAS

Kansas UAP-Parsons
Parsons Research Center
Parsons, KS 67357
(316) 421-6550
(316) 421-1864 (fax)
http://www.lsi.ukans.edu/uap/uap.htm

University of Kansas
Institute for Life Span Studies
1052 Dole Human Development Center
Lawrence, KS 66045
(913) 864-4950
(913) 864-5338 (fax)
http://www.lsi.ukans.edu/uap/uap.htm

University of Kansas Medical Center
Ralph L. Smith Mental Retardation Research Center
3901 Rainbow Blvd
Kansas City, KS 66160
(913) 588-5900
(913) 588-5677 (fax)
http://www.lsi.ukans.edu/uap/uap.htm

KENTUCKY

University of Kentucky UAP
Human Development Institute
Lexington, KY 40506-0051
(606) 257-1714
(606) 258-1901 (fax)
http://www.ihdi.uky.edu/

LOUISIANA

University of Louisiana UAP
School of Allied Health Professionals
1100 Florida Ave
New Orleans, LA 70119-2799
(504) 942-8200
(504) 942-8305 (fax)
http://www.hdc.lsumc.edu/hdc02/

MAINE

University of Maine UAP
Center for Community Inclusion
5717 Corbert Hall, Rm 100
Orono, ME 04469-5717
(207) 581-1084
(207) 581-3328 (TDD)
(207) 581-1231 (fax)
http://www.ume.maine.edu/~cci

MARYLAND

Kennedy Krieger Institute
Center for Leadership in Disabilities
707 N. Broadway
Baltimore, MD 21213
(888) 554-2080
(410) 502-9524 (fax)
http://www.kennedykrieger.org

MASSACHUSETTS

Eunice Shriver Center
University Affiliated Program
Waltham, MA 02254
(781) 642-0230
(781) 893-5340 (fax)
http://www.shriver.org/Service/CommunityFamilyService/index.htm

University of Massachusetts, Boston
Graduate College of Education
100 Morrisey Blvd
Boston, MA 02125-3393
(617) 287-7645
(617) 287-7664 (fax)

Institute for Community Inclusion UAP
Children's Hospital
300 Longwood Ave
Boston, MA 02115
(617) 355-6509
(617) 355-7940 (fax)
http://www.childrenshospital.org/ici

MICHIGAN

Wayne State University
Developmental Disabilities Institute
Detroit, MI 48202
(313) 577-2654
(313) 577-3770 (fax)
http://www..ddi.wayne.edu

MINNESOTA

University of Minnesota
Institute on Community Integration
100 Pattee Hall
150 Pillsbury Drive Southeast
Minneapolis, MN 55455
(612) 624-6300
(612) 625-6619 (fax)
http://www.ici.coled.umn.edu

Institute for Health and Disability
Box 721
420 Delaware Street Southeast
Minneapolis, MN 55455
(612) 626-2134
(612) 626-2134 (fax)

MISSISSIPPI

University of Southern Mississippi UAP
Institute for Disability Studies
2701 Hardy St.
Hattiesburg, MS 39406-5163
(601) 266-5163
(601) 266-5114 (fax)
http://www-dept.usm.edu/~idstu

MISSOURI

University of Missouri-Kansas City
Institute for Human Development
2220 Holmes St., 3rd floor
Kansas City, MO 64108
(816) 235-1770
(816) 235-1762 (fax)
http://www.umkc.edu/ihd

MONTANA

University of Montana UAP
Montana University Affiliated Rural Institute on Disabilities Program
52 Corlan Hall
Missoula, MT 59812
(406) 243-5467
(406) 243-4730 (fax)
http://ruralinstitute.umt.edu/

NEBRASKA

Nebraska UAP
Munroe - Meyer Institute
Omaha, NE 68198-5450
(402) 559-6430
(402) 559-5737 (fax)
http://www.unmc.edu/mmi

NEVADA

Nevada UAP
Research and Educational
Planning Center
Reno, NV 89557-0082
(775) 784-4921 (775) 784-4997 (fax)
http://www.unr.edu/repc/uap

NEW HAMSPIRE

University of New Hampshire
Institute on Disability UAP
7 Lavit Lane, Ste. 101
Durham, NH 03824-3522
(603) 862-4320 (603) 862-0555 (fax)
http://www.iod.unh.edu

NEW JERSEY

New Jersey UAP, Boggs Center
Robert Wood Johnson
Medical School
New Brunswick, NJ 08901-2013
(732) 235-9300 (732) 235-9330 (fax)
http://www.umdnj.edu

NEW MEXICO

University of New Mexico
Center for Development
and Disability
Albuquerque, NM 87107
(505) 272-3000 (505) 272-5280 (fax)
http://cdd.unm.edu/resource

NEW YORK

Rose F. Kennedy Center
Albert Einstein School of Medicine
of Yeshiva University
1300 Morris Park Ave.
Bronx, NY 10461
(718) 430-8522 (718) 892-2296 (fax)
http://www.aecom.yu.edu

Westchester Institute for Human Development
Valhalla, NY 10595
(914) 493-8204 (914) 493-1973 (fax)
http://www.nymc.edu/wind

University of Rochester UAP
Strong Center for Developmental
Disabilities
601 Elmwood Ave.
Rochester, NY 14642
(716) 275-0355 (716) 275-3366 (fax)
http://www.urmc.rochester.edu/strong/scdd

NORTH CAROLINA

University of North Carolina, Chapel Hill
Center for the Study of Development
and Learning
CB 7255
Chapel Hill, NC 27599-7255
(919) 966-5171 (919) 966-2230 (fax)
http://cdl.unch.unc.edu

NORTH DAKOTA

Minot State University
The North Dakota Center for
Persons with Disabilities
Minot, ND 58707
(701) 858-3580 (701) 858-3483 (fax)
http://www.ndcd.org

OHIO

Ohio State University
The Nisonger Center
1581 Dodd Drive
Columbus, OH 43210-1296
(614) 292-8365 (614) 292-3727 (fax)

University of Cincinnati UAP
University Affiliated Cincinnati Center
for Developmental Disorders
Pavillion Building
3333 Burnett Ave
Cincinnati, OH 45229-3039
(513) 636-8383 (513) 636-7361 (fax)
http://www.cincinnatichildrens.org

OKLAHOMA

University of Oklahoma UAP
Health Sciences Center
1100 N. Lindsay
Oklahoma City, OK 73104
(405) 271-4500 (405) 271-3087 (fax)
http://main.ouhsc.edu/

OREGON

Oregon Institute on Disability & Development
Child Development and
Rehabilitation Center
Oregon Health Sciences University
P.O. Box 574
707 S.W. Gaines Rd.
Portland, OR 97201
(503) 494-8364 (503) 494-6868 (fax)
E-mail: UAP@ohsu.edu
http://www.ohsu.edu/cdrc/uap/index.html

University of Oregon, Eugene
Center on Human Development
Eugene, OR 97403-1265
(503) 346-3591 (503) 346-5639 (fax)
http://interact.uoregon.edu/uap/uap.html

PACIFIC BASIN PROGRAM

American Samoa Community College
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(011) 684-699-9155
(011) 684-699-2062 (fax)

Northern Marianas College
Commonwealth of the Northern
Marianas Site
Saipan, NM 96950
(670) 234-5498 (670)234-0759 (fax)

PENNSYLVANIA

Temple University
Institute on Disabilities/UAP
Ritter Hall Annex, Rm 423
13th and Cecil B. Moore Ave.
Philadelphia, PA 19122
(215) 204-1356 (215) 204-6336 (fax)
http://www.temple.edu/inst_disabilities

University of Pittsburgh
Rangos Research Center
3705 Fifth Ave, 3rd floor
Pittsburgh, PA 15213-2583
(412) 692-6300 (412) 692-8729 (fax)
http://www.pitt.edu/uclid/ucdhome.htm

Children's Seashore House
University of Pennsylvania
School of Medicine
Philadelphia, PA 19104
(215) 895-3700 (215) 895-3605 (fax)
http://www.childrens-seashore.org

PUERTO RICO

University of Puerto Rico
Medical Sciences Campus
San Juan, PR 00936-5067
(787) 754-4377 (787) 759-6719 (fax)

RHODE ISLAND

Rhode Island UAP
Rhode Isaind College
Institute for Developmental Disabilities
600 Mount Pleasant Ave.
Providence, RI 02908
(401) 456-8024 (401) 456-8072 (fax)

SOUTH CAROLINA

University of South Carolina UAP
Center for Disability Resources
8301 Farrow Road
Sequoia Building
Columbia, SC 29208
(803) 935-5248 (803) 935-5059 (fax)
http://www.cdd.sc.edu/

SOUTH DAKOTA

University of South Dakota UAP
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1400 W. 22nd St
Sioux Falls, SD 57105
(605) 357-1439 (605) 357-1438 (fax)
http://www.usd.edu/sduap/home.html

TENNESSEE

University of Tennessee UAP
Boling Center for Developmental
Disabilities
711 Jefferson Avenue
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http://www.utmem.edu/bcdd/boling.html

TEXAS

University of Texas at Austin
Texas University Affiliated Program
George L. Sanchez Building, Rm 252
Austin, TX 78712-1290
(512) 471-7621 (512) 471-7549 (fax)
http://uap.edb.utexas.edu/

UTAH

Utah State University
Center for Persons with Disabilities
6800 Old Main Hill
Logan, UT 84322-6800
(801) 797-1981 (801) 797-3944 (fax)
http://www.cpd.usu.edu

VERMONT

University of Vermont
University Affiliated Program of
Vermont
Waterman Building, Rm 499C
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(802) 656-4031 (802) 656-1357 (fax)
http://www.uvm.edu/~uapvt/

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Virginia Institute for Developmental
Disabilities
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Richmond, VA 23284-3020
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http://www.vcu.edu/vidd/

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University of the Virgin Islands UAP
Division of Education
St. Thomas, VI 00802-9990
(340) 693-1323
(340) 693-1325 (fax)

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Center on Human
Development and Disability
P.O. Box 357920
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http://depts.washington.edu/chdd

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Circle #55

Alliance for Technology Access Centers

The Alliance for Technology Access (ATA) began in 1987 as a joint project of a grass-roots organization, the Disabled Children's Computer Group, and a major corporation, Apple Computer™. From this small group of parents, consumers, and professionals, the ATA has grown into one of the nation's largest resources to help children and adults who have disabilities, gain access to the benefits of adaptive technology.

The ATA's most important means of promoting technology access may be its nationwide network of community-based assistive technology resource centers. ATA centers work with a wide variety of individuals and organizations and have no eligibility criteria for determining who may receive service. Most centers provide hands-on consultations, product demonstrations, make recommendations and referrals, and present workshops on technology use.

This listing was provided by the ATA (for the main office, see first listing below). When available, World Wide Web sites and e-mail addresses have been included. Web sites are listed with the standard **http://** before each. E-mail addresses are indicated by the symbol, ✉. (Unless otherwise indicated, all telephone numbers are for voice only.)

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National Office
Technology Access Center
2175 E. Francisco Blvd., Ste. L
San Rafael, CA 94901
(415) 455-4575
(415) 455-0491 (TTY)
(415) 455-0654 (fax)
http://www.ATAccess.org
✉ ATAinfo@ATAccess.org

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Birmingham Alliance for Technology Access Center
Birmingham Independent
Living Center
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Birmingham, AL 35233-1317
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(205) 251-0605 (fax)
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(256) 532-2355
✉tasc@travellers.com

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Alaska Services for Enabling Technology
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✉asetseak@aol.com

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Technology Access Center of Tucson, Inc.
PO Box 13178
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(520) 790-7637 (fax)
✉tactaz@aol.com

ARKANSAS

Arkansas Easter Seals Technology Resource Center
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Little Rock, AR 72212-2495
(501) 227-3602
(501) 227-3601 (fax)
http://www.arkeasterseals.org
✉atrce@aol.com

CALIFORNIA

Center for Accessible Technology
2547 8th St., 112-A
Berkeley, CA 94710-2572
(510) 841-3224
(510) 841-5621 (BBS)
(510) 841-7956 (fax)
http://www.el.net/CAT
✉cforat@aol.com

Computer Access Center
5901 Green Valley Cir, Ste. 320
Culver City, CA 90230
(310) 338-1597
(310) 338-9318 (fax)
http://www.cac.org
✉cac@cac.org

ITECH Parents Helping Parents
3041 Olcott St.
Santa Clara, CA 95054-3222
(408) 727-5775
✉ITECH@php.com

SACC—Assistive Technology Center Simi Valley Hospital Rehab Unit North
PO Box 1325
Simi Valley, CA 93062
(805) 582-1881
(805) 582-2855 (fax)
✉dssaccca@aol.com

Sacramento Center for Assistive Technology
701 Howe Ave., Ste. E-5
Sacramento, CA 95825
(916) 927-7228
http://www.quicknet.com/~scat
✉scatca@quicknet.com

San Diego Assistive Technology Center
3821 Calle Fortunada, Suite C
San Diego, CA 32123
(858) 571-7803
✉ucpsdatc@pacbell.net

Team of Advocates for Special Kids
100 W. Cerritos Ave.
Anaheim, CA 92805
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(714) 533-2533
(714) 533-2533 (fax)
✉taskca@aol.com

FLORIDA

CITE/Center for Independence Technology & Education
215 E. New Hampshire St.
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(407) 895-5255 (fax)
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GEORGIA

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(770) 922-6769 (fax)
http://www.onramp.net/tech-able
✉techable@america.net

HAWAII

Aloha Special Technology Access Center
710 Green St.
Honolulu, HI 96813
(808) 523-5547
(808) 536-3765 (fax)
http://www.aloha.net/~stachi/
✉stachi@aol.com

IDAHO

United Cerebral Palsy of Idaho, Inc.
5530 W. Emerald
Boise, ID 83706
(208) 377-8070
(208) 322-7133 (fax)
✉ucpidaho@aol.com

ILLINOIS

Northern Illinois Center for Adaptive Technology
3615 Louisiana Rd.
Rockford, IL 61108-6195
(815) 229-2163
(815) 229-2135 (fax)
✉ilcat@aol.com

Technical Aids & Assistance for the Disabled Center
1950 W. Roosevelt Road
Chicago, IL 60608
(312) 421-3373 (voice/TTY)
(312) 421-3464 (fax)
homepage.interaccess.com/~taad
✉taad@interaccess.com

INDIANA

Assistive Technology Training and Information Center
3354 Pine Hill Dr.
PO Box 2441
Vincennes, IN 47591
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(812) 886-11128 (fax)
✉inattic1@aol.com

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Salina, KS 67402-1160
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(785) 323-2015 (fax)
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KENTUCKY

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169 N. Limestone St.
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(606) 255-9951 (V/TTY)
(606) 255-0069 (fax)
✉Bluegrass@uky.campus.mci.net

EnTech: Enabling Technologies of Kentuckiana
301 York St.
Louisville, KY 40203-2257
(502) 574-1637
http://www.kde.state.ky.us/assistive/
home.htm
✉entech@iglou.com

Western Kentucky Assistive Technology Consortium
PO Box 266
607 Poplar St., Ste. 207
Murray, KY 42071
(502) 759-4233
(502) 759-4208 (fax)
✉wkatc@mursuky.campus.mci.net

MARYLAND

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(410) 659-5472 (fax)
✉lincmd@aol.com

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(517) 224-0330 (fax)
✉matr@match.org

MINNESOTA

PACER Computer Resource Center
4826 Chicago Ave S
Minneapolis, MN 55417-1098
(612) 827-2966 (voice/TTY)
(517) 224-0330 (fax)
http://www.pacer.org/crc/crc.htm
✉crcenter@pacer.org

MISSOURI

Technology Access Center
12110 Clayton Rd.
St. Louis, MO 63130
(314) 569-8404
(314) 569-8446 (TTY)
(314) 569-8449 (fax)
✉mostltac@aol.com

MONTANA

Parents, Let's Unite for Kids
516 N. 32nd St.
Billings, MT 59101
(800) 222-7585 (MT only)
(406) 255-0540

NEW JERSEY

The Center for Enabling Technology
622 Rt. 10 W, Ste. 22B
Whippany, NJ 07981
(973) 428-1455
(973) 428-1450 (TTY)
(973) 560-9751 (fax)
✉cetnj@aol.com

Computer Center for People With disAbilities
c/o Family Resource Associates, Inc.
35 Haddon Ave.
Shrewsbury, NJ 07702-4007
(732) 747-5310
(732) 747-1896 (fax)
✉ccdanj@aol.com

NEW YORK

Techspress Resource Center for Independent Living
401-409 Columbia St.
PO Box 210
Utica, NY 13503-0210
(315) 797-4642
(315) 797-4747 (fax)
✉lana.gossin@rcil.com

NORTH CAROLINA

Carolina Computer Access Center Metro School
700 E. 2nd St.
Charlotte, NC 28202-2826
(704) 342-3004
(704) 342-1513 (fax)
✉ccacnc@aol.com

OHIO

Technology Resource Center
2049 Harshman Rd.
Dayton, OH 45424
(937) 236-3305
(937) 236-6110 (TDD)
(937) 236-3119 (fax)
trcdoh@aol.com
✉www.trcd.org

RHODE ISLAND

TechACCESS Center of Rhode Island
100 Jefferson Blvd
Warwick, RI 02888
(401) 273-0202 (voice/TTY)
(401) 463-3433 (fax)
✉techaccess@techaccess-ri.org

TENNESSEE

East Tennessee Technology Access Center, Inc.
3525 Emory Rd. NW
Powell, TN 37849
(423) 947-2191 (voice/TTY)
(423) 947-2194 (fax)
http://www.kormet.org/ettac/
✉etstactn@aol.com

Mid-South Access Center for Technology
University of Memphis,
College of Education
Room 307B Ball Hall
Memphis, TN 37228
(901) 678-3919
✉kanderso@memphis.edu

Technology Access Center of Middle Tennessee
2222 Metrocenter Blvd., Ste. 126
Nashville, TN 37228
(615) 248-6733 (voice/TTY)
(615) 259-2536 (fax)
✉ tactn@nashville.com

West Tennessee Special Technology Access Resource Center
60 Lynoak Cove
Jackson, TN 38305
(901) 668-3888, (901) 668-1666 (fax)
http://www.starcenter.tn.org
✉mdoumitt@starcenter.tn.org

UTAH

The Computer Center for Citizens with Disabilities
c/o UT Center for Assistive Technology
2056 S. 1100 E.
Salt Lake City, UT 84106
(801) 485-9152 (voice/TTY)
(801) 485-8675 (fax)
✉cboogaar@usoe.k12.ut.us

VIRGIN ISLANDS

Virgin Islands Resource Center for the Disabled
P.O. Box 308427
St. Thomas, USVI 00803-8427
(340) 777-2253
(340) 774-9330 (fax)
http://www.vircd.ataccess.org
✉vircd@islands.vi

VIRGINIA

Tidewater Center for Technology Access
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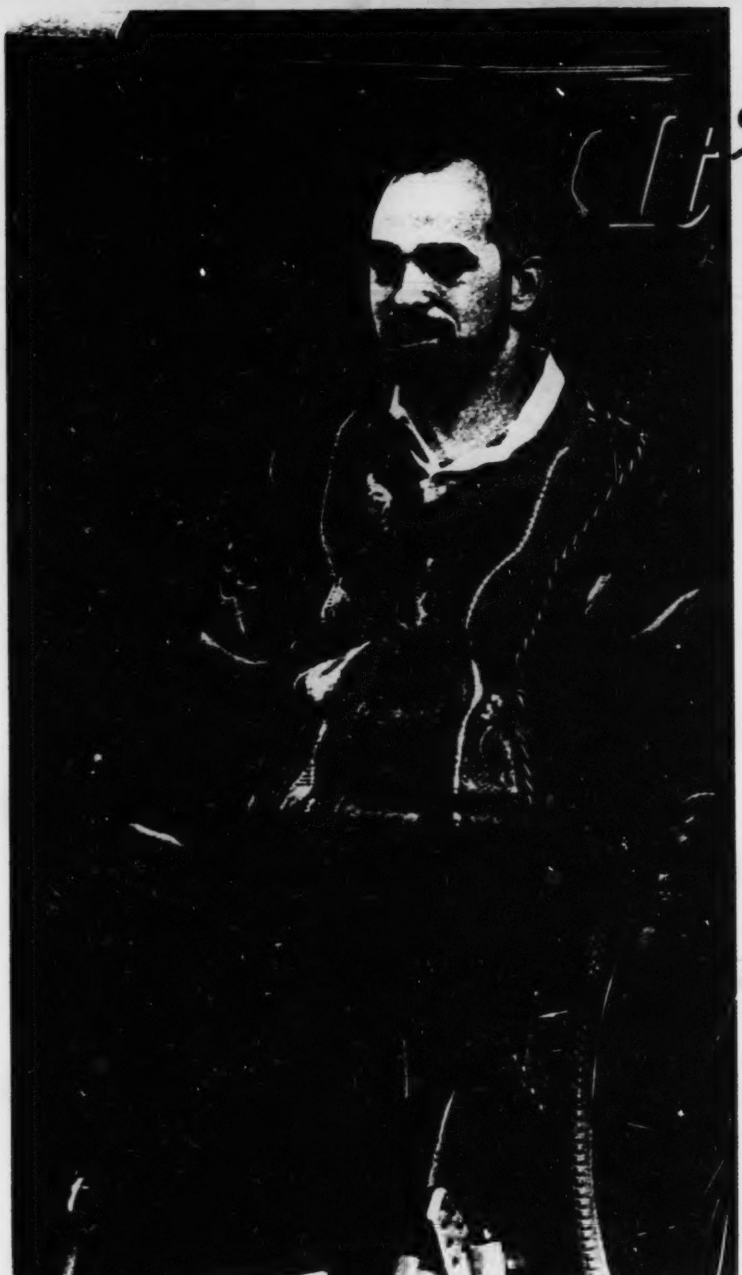

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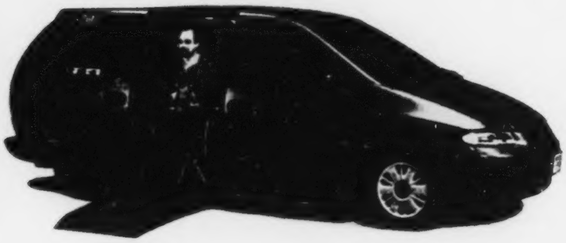

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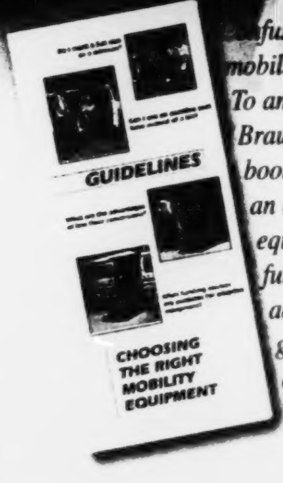

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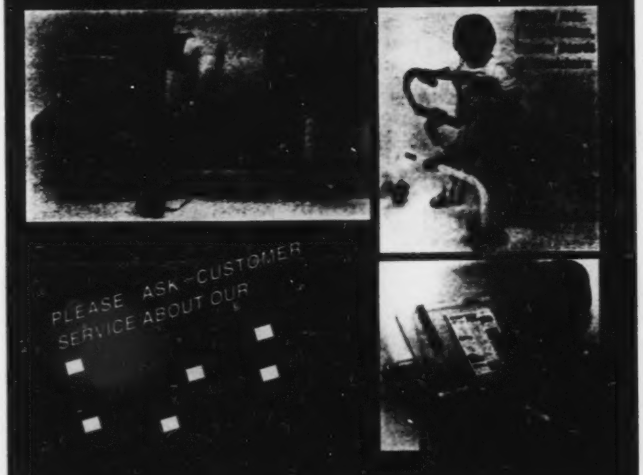

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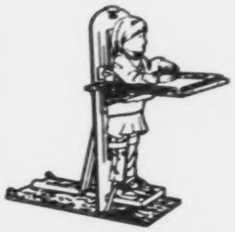

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Circle #49

State Assistive Technology Programs

The following state assistive technology programs are funded by the National Institute on Disability and Rehabilitation Research (NIDRR) under the Assistive Technology Act of 1998 (P.L. 105-394). For more information, contact: RESNA Technical Assistance Project, 1700 North Moore St., Ste. 1540, Arlington, VA 22209-1903; (703) 524-6686 (voice); (703) 524-6630 (TTY); (703) 524-6630 (fax); e-mail: resnata@resna.org. You may also wish to check out the project's Web site: http://www.resna.org/taproject.

When available, e-mail addresses and World Wide Web sites have been included. E-mail addresses are indicated by the symbol, ✉. Web sites are listed with the standard **http://** before each. (Unless otherwise indicated, telephone numbers are for voice only.)

ALABAMA

ALABAMA STATEWIDE TECHNOLOGY ACCESS AND RESPONSE PROJECT (STAR) SYSTEM FOR ALABAMIANS WITH DISABILITIES
2125 E. South Blvd.
PO Box 20752
Montgomery, AL 36120-0752
(334) 613-3480
(800) STAR656 (In-State)
(334) 613-3519 (TTY)
(334) 613-3485 (fax)
✉tbridges@rehab.state.al.us
http://www.rehab.state.al.us/star

ALASKA

ASSISTIVE TECHNOLOGIES OF ALASKA
1016 W. 6th, Ste 200
Anchorage, AK 99501
Information and Referral:
(907) 563-0138 (V/TTY)
(907) 269-3632 (fax)
✉james_beck@educ.state.ak.us
http://www.labor.state.ak.us/ata/index.htm

AMERICAN SAMOA

ASSISTIVE TECHNOLOGY SERVICE PROJECT (ASATS)
Division of Vocational Rehabilitation
Department of Human Resources
Pago Pago, American Samoa 96799
(684) 699-1529
(684) 233-7874 (TTY)
(684) 699-1376 (fax)
✉EdPerei@yahoo.com

ARIZONA

ARIZONA TECHNOLOGY ACCESS PROGRAM (AZTAP)
Institute for Human Development
Northern Arizona University
PO Box 5630
Flagstaff, AZ 86011
(520) 523-8779
(520) 523-1695 (TTY)
(520) 523-9127 (fax)
✉jill.oberstein@nau.edu
http://www.nau.edu/~ihd/aztap

ARKANSAS

ARKANSAS INCREASING CAPABILITIES ACCESS NETWORK (ICAN)
Arkansas Dept. of Workforce Education
Arkansas Rehabilitation Services
2201 Brookwood Drive, Suite 117
Little Rock, AR 72202
(501) 666-8868 (V/TTY)
(800) 828-2799 (V/TTY, In-State)
(501) 666-5319 (fax)
✉sogaskin@ars.state.ar.us
http://www.arkansas-ican.org

CALIFORNIA

CALIFORNIA ASSISTIVE TECHNOLOGY SYSTEM
California Department of Rehabilitation
2000 Evergreen
Sacramento, CA 95815
Mailing Address:
PO Box 944222
Sacramento, CA 94244-2220
(916) 263-8687
(916) 263-8685 (TTY)
(916) 263-8683 (fax)
✉dor_dlaw@yahoo.com
http://www.catsca.org

COLORADO

COLORADO ASSISTIVE TECHNOLOGY PROJECT
University of Colorado Health Sciences Center
Colorado University Affiliated Program
The Pavilion, A036/B140
1919 Ogden Street, 2nd Floor
Denver, CO 80218
(303) 864-5100
(303) 864-5110 (TTY)
(303) 864-5119 (fax)
✉ cathy.bodine@UCHSC.edu
http://www.uchsc.edu/catp

CONNECTICUT

CONNECTICUT ASSISTIVE TECHNOLOGY PROJECT
Department of Social Services, BRS
25 Sigourney St., 11th Floor
Hartford, CT 06106
(860) 424-4881
(800) 537-2549 (In-State)
(860) 424-4839 (TTY)
(860) 424-4850 (fax)
✉ cttap@aol.com
http://www.techact.uconn.edu

DELAWARE

DELAWARE ASSISTIVE TECHNOLOGY INITIATIVE (DATI)
Center for Applied Science & Engineering
University of Delaware/duPont Hospital for Children
1600 Rockland Road, Room 117E
PO Box 269
Wilmington, DE 19899-0269
(302) 651-6790
(800) 870 DATI (3284) (In-State)
(302) 651-6794 (TTY)
(302) 651-6793 (fax)
✉ dati@asel.udel.edu
http://www.asel.udel.edu/dati/

DISTRICT OF COLUMBIA

UNIVERSITY LEGAL SERVICES AT PROGRAM FOR THE DISTRICT OF COLUMBIA
300 I Street, NE, Ste 200
Washington, DC 20002
(202) 547-0198
(202) 547-2657 (TTY)
(202) 547-2662 (fax)
✉ajohns@ULS-DC.com
http://www.atpdc.org

FLORIDA

FLORIDA ALLIANCE FOR ASSISTIVE SERVICE AND TECHNOLOGY
1020 E. Lafayette St., Suite 110
Tallahassee, FL 32301-4546
850) 487-3278 (V/TTY)
(850) 487-2805 (fax/TTY)
✉faast@faast.org
http://www.faast.org

GEORGIA

GEORGIA TOOLS FOR LIFE
Division of Rehabilitation Services
2 Peachtree Street NW, Ste 35-415
Atlanta, GA 30303-3142
(404) 657-3084
(800) 497-8665 (In-State)
(404) 657-3085 (TTY)
(404) 657-3086 (fax)
✉ toolsforlife@mindspring.com
http://www.gatfl.org

GUAM

GUAM SYSTEM FOR ASSISTIVE TECHNOLOGY (GSAT)
University of Guam, UOG Station
303 University Drive
Mangilao, Guam 96923
(671) 735-2490
(671) 734-8378 (TTY)
(671) 734-5709 (fax)
✉ gsat@ite.net
http://www.uog2.uog.edu/uap/gsat.html

HAWAII

HAWAII ASSISTIVE TECHNOLOGY TRAINING AND SERVICES (HATTS)
414 Kuwili Street, Suite 104
Honolulu, HI 96817
808) 532-7110 (V/TTY)
(800) 645-3007 (V/TTY, In-State)
(808) 532-7120 (fax)
✉hatts@hatts.org
http://www.hatts.org

IDAHO

IDAHO ASSISTIVE TECHNOLOGY PROJECT
129 W. Third Street
Moscow, ID 83844-4401
(208) 885-3630
(208) 885-3559 (V/TTY)
(208) 885-3628 (fax)
✉ seile861@uidaho.edu
http://www.ets.uidaho.edu

ILLINOIS

ILLINOIS ASSISTIVE TECHNOLOGY PROJECT
1 W. Old State Capitol Plaza
Suite 100
Springfield, IL 62701
(217) 522-7985
(217) 522-9966 (TTY)
(217) 522-8067 (fax)
✉gunther@midwest.net
http://www.iltech.org

INDIANA

INDIANA ATTAIN (AASSISTIVE TECHNOLOGY THROUGH ACTION IN INDIANA) PROJECT
1815 N.Meridian St., Ste. 200
Indianapolis, IN 46202
(217) 921-8766
(800) 528-8246 (In-State)
(800) 743-3333 (TTY, National)
(217) 921-8774 (fax)
✉ clufford@indian.vinu.edu
http://www.vinu.edu/attain

IOWA

IOWA PROGRAM FOR ASSISTIVE TECHNOLOGY
Iowa University Affiliated Program
University Hospital School
100 Hawkins Drive, Rm S295
Iowa City, IA 52242-1011
(319) 356-4463
(800) 331-3027 (V/TTY, National)
(319) 384-9273 (fax)
✉mary-quigley@uiowa.edu
jane-gay@uiowa.edu
http://www.uiowa.edu/infotech

KANSAS

ASSISTIVE TECHNOLOGY FOR KANSANS PROJECT
2601 Gabriel
PO Box 738
Parsons, KS 67357
(316) 421-6550 ext. 1890
✉cspellman@parsons.lsi.ukans.edu
(316) 421-8367
(800) KAN DO IT
(316) 421-0954 (fax, TTY)
✉ssack@parsons.lsi.ukans.edu
http://www.atk.lsi.ukans.edu

KENTUCKY

KENTUCKY ASSISTIVE TECHNOLOGY SERVICE NETWORK
Charles McDowell Center
8412 Westport Road
Louisville, KY 40242
(502) 327-0022
(800) 327-5287 (V/TTY, In-State)
(502) 327-9974 (fax)
(502) 327-9855 (TTY)
✉katsnet@iglou.com
http://www.katsnet.org

LOUISIANA

LOUISIANA ASSISTIVE TECHNOLOGY ACCESS NETWORK
PO Box 14115
Baton Rouge, LA 70898-4115
(225) 925-9500 (V/TTY)
(800) 270-6185 (V/TTY)
(225) 925-9560 (fax)
✉jnesbit@latan.org
http://www.latan.org

MAINE

MAINE CONSUMER INFORMATION AND TECHNOLOGY TRAINING EXCHANGE (MAINE CITE)
Maine CITE Coordinating Center
University of Maine System Network
46 University Drive
Augusta, ME 04330
(207) 621-3195 (V/TTY)
(207) 621-3193 (fax)
✉kpowers@maine.caps.maine.edu
http://www.mecite.doe.k12.me.us

MARYLAND

MARYLAND TECHNOLOGY ASSISTANCE PROGRAM
Governor's Office for Individuals with Disabilities
2301 Argonne Drive
RM T17
Baltimore, MD 21218
(800) 832-4827
(410) 554-9230 (V/TTY)
(410) 554-9237 (fax)
✉rasinski@clark.net
http://www.mdtap.org

MASSACHUSETTS

MASSACHUSETTS ASSISTIVE TECHNOLOGY PARTNERSHIP
MATP Center
Children's Hospital
1295 Boylston Street, Suite 310
Boston, MA 02115
(617) 355-7820 (TTY)
(800) 848-8867 (V/TTY, In-State)
(617) 355-7153
(617) 355-6345 (fax)
✉matp@matp.org
http://www.matp.org

MICHIGAN

MICHIGAN TECH 2000
Michigan Assistive Technology Project
740 W. Lake Lansing Rd., Suite 400
East Lansing, MI 48823
(517) 333-2477 (V/TTY)
(800) 760-4600 (In-State)
(517) 333-2677 (fax)
✉roanne@sprynet.com
http://www.copower.org

MINNESOTA

MINNESOTA STAR PROGRAM
300 Centennial Building
658 Cedar Street
St. Paul, MN 55155
(800) 657-3862 (In-State)
(800) 657-3895 (TTY) (In-State)
(651) 296-2771
(651) 296-9478 (TTY)
(651) 282-6671 (fax)
✉ star.program@state.mn.us
http://www.state.mn.us/ebranch/admin/assistivetechnology/index.html

MISSISSIPPI

MISSISSIPPI PROJECT START
PO Box 1698
Jackson, MS 39215-1000
(601) 987-4872
(800) 852-8328 (V/TTY; In-State)
(601) 364-2349 (fax)
✉ spower@netdoor.com

MISSOURI

MISSOURI ASSISTIVE TECHNOLOGY PROJECT
4731 South Cochise, Suite 114
Independence, MO 64055-6975
(800) 647-8557 (In-State)
(660) 373-5193
(660) 373-9315 (TTY)
(660) 373-9314 (fax)
✉ matpmo@gni.com
http://www.dolir.state.mo.us/matp/

MONTANA

MONTECH
Rural Institute on Disabilities
The University of Montana
634 Eddy Avenue
Missoula, MT 59812
(406) 243-5676
(800) 732-0323 (TTY; National)
(406) 243-4730 (fax)
✉ montech@selway.umt.edu
http://ruralinstitute.umt.edu/

NEBRASKA

NEBRASKA ASSISTIVE TECHNOLOGY PARTNERSHIP
5143 South 48th Street, Suite C
Lincoln, NE 68516-2204
(402) 471-0734 (V/TTY)
(402) 471-0735 (V/TTY)
(888) 806-6287 (In-State)
(402) 471-6052 (fax)
✉ mschultz@atp.state.ne.us
http://www.edneb.org

NEVADA

NEVADA ASSISTIVE TECHNOLOGY COLLABORATIVE
Rehabilitation Division
Community Based Services
711 South Stewart Street
Carson City, NV 89710
(775) 687-4452
(775) 687-3388 (TTY)
(775) 687-3292 (fax)
✉ pgowins@govmail.state.nv.us
http://www.state.nv.us.80

NEW HAMPSHIRE

NEW HAMPSHIRE TECHNOLOGY PARTNERSHIP PROJECT
Institute on Disability/UAP
#14 Ten Ferry Street
NEW HAMPSHIRE
The Concord Center
Concord, NH 03301
603) 862-4320
(603) 224-0630 (V/TTY)
(800) 427-3338 (V/TTY) (In-State)
(603) 226-0389 (fax)
✉ twillkomm@nnaat.mv.com
http://www.iod.unh.edu/projects/spd.htm

NEW JERSEY

NEW JERSEY TECHNOLOGY ASSISTIVE RESOURCE PROGRAM (NJTARP)
New Jersey Protection and Advocacy, Inc.
210 South Broad Street, 3rd Floor
Trenton, NJ 08608
(609) 777-0945
(800) 342-5832 (In-State)
(609) 633-7106 (TTY)
(609) 777-0187 (fax)
✉ packro@njpanda.org
http://www.njpanda.org

NEW MEXICO

NEW MEXICO TECHNOLOGY ASSISTANCE PROGRAM
435 St. Michael's Drive, Building D
Santa Fe, NM 87505
(800) 866- 2253
(505) 954-8539 (TTY)
(505) 954-8562 (fax)
✉ aklaus@state.nm.us
http://www.nmtap.com

NEW YORK

NEW YORK STATE TRAID PROJECT
Office of Advocate for Persons with Disabilities
One Empire State Plaza, Suite 1001
Albany, NY 12223-1150
(518) 474-2825
(800) 522-4369 (V/TTY; In-State)
(518) 473-4231 (TTY)
(518) 473-6005 (fax)
✉ traid@emi.com
http://www.state.ny.us/disabled-Advocate/technlog.htm

NORTH CAROLINA

NORTH CAROLINA ASSISTIVE TECHNOLOGY PROJECT
Department of Health and Human Services
Division of Vocational Rehabilitation Services
1110 Navaho Drive, Suite 101
Raleigh, NC 27609-7322
(919) 850-2787 (V/TTY)
(919) 850-2792 (fax)
✉ nckic@mindspring.com
http://www.mindspring.com/~ncatp

NORTH DAKOTA

NORTH DAKOTA INTERAGENCY PROGRAM FOR ASSISTIVE TECHNOLOGY (IPAT)
PO Box 743
Cavalier, ND 58220
(701) 265-4807 (V/TTY)
(701) 265-3150 (fax)
✉ lee@pioneer.state.nd.us
http://www.ndipat.org

NORTHERN MARIANA ISLANDS

COMMONWEALTH OF THE NORTHERN MARIANA ISLANDS ASSISTIVE TECHNOLOGY PROJECT
Governor's Developmental Disabilities Council, Systems of Technology-Related Assistance for Individuals with Disabilities
PO Box 2565 CK
Saipan, MP 96950
(670) 664-7005 (V/TTY)
(670) 664-7010 (fax)
✉ gddc@cnmiddcouncil.org
http://www.cnmiddcouncil.org

OHIO

ASSISTIVE TECHNOLOGY OF OHIO
Ohio Super Computer Center
1224 Kinnear Road
Columbus, OH 43212
(614) 292-2426 (V/TTY)
(800) 784-3425 (V/TTY, In-State)
(614) 292-3162 (TTY)
(614) 292-5866 (fax)
✉ hunitt.1@osc.edu
http://www.train.state.oh.us

OKLAHOMA

OKLAHOMA ABLE TECH
Oklahoma State University Wellness Center
1514 W. Hall of Fame Road
Stillwater, OK 74078-2026
(405) 744-9864
(405) 744-9748
(800) 257-1705 (V/TTY)
(405) 744-2487
✉ mljwell@okway.ok.state.edu
http://www.okstate.edu/wellness/at-home.htm

OREGON

OREGON TECHNOLOGY ACCESS FOR LIFE NEEDS PROJECT (TALN)
c/o Access Technologies Inc.
3070 Lancaster Drive NE
Salem, OR 97305-1396
(503) 361-1201 (V/TTY)
(800) 677-7512 (In-State)
(503) 370-4530 (fax)
✉ ati@orednet.org
http://www.taln.ncn.com

PENNSYLVANIA

PENNSYLVANIA'S INITIATIVE ON ASSISTIVE TECHNOLOGY
Institute on Disabilities/UAP
Ritter Annex 423
Philadelphia, PA 19122
(800) 204-PIAT (7428)
(800) 750-PIAT (TTY)
(215) 204-9371 (fax)
✉ piat@astro.temple.edu
http://www.temple.edu/inst_disabilities

PUERTO RICO

PUERTO RICO ASSISTIVE TECHNOLOGY PROJECT
University of Puerto Rico
Medical Sciences Campus
College of Related Health Professions
Office of Project Investigation and Development, Box 365067
San Juan, PR 00936-5067
(800) 496-6035 (National)
(800) 981-6033 (In PR)
(787) 754-8034 (fax; TTY)
✉ pratp@coqui.net

RHODE ISLAND

RHODE ISLAND ASSISTIVE TECHNOLOGY ACCESS PARTNERSHIP
Office of Rehabilitation Services
40 Fountain Street
Providence, RI 02903
(401) 421-7005 x310
(800) 752-8088 x2608 (In-State)
(401) 421-7016 (TTY)
(401) 421-9259 (fax)
✉ solson@atap.state.ri.us
http://www.atap.state.ri.us/

SOUTH CAROLINA

SOUTH CAROLINA ASSISTIVE TECHNOLOGY PROGRAM
USC School of Medicine
Center for Developmental Disabilities
8301 Farrow Rd.
Columbia, SC 29208
(803) 935-5263 (V/TTY)
(803) 935-5342 (fax)
✉ kingm@cdd.sc.edu
http://www.public.usit.net/jjendron/

SOUTH DAKOTA

SOUTH DAKOTA ASSISTIVE TECHNOLOGY PROJECT (DAKOTALINK)
221 S. Central
Pierre, SD 57501
(605) 224-5336 (V/TTY)
(800) 224-5336 (V/TTY, In-State)
(605) 224-8320 (fax)
✉ davev@tie.net
http://www.tie.net/dakotalink

TENNESSEE

TENNESSEE TECHNOLOGY ACCESS PROJECT (TTAP)
Department of MH/MR
Division of Mental Health
Andrew Johnson Tower, 10th Floor
710 James Robertson Parkway
Nashville, TN 37243-0675
(615) 532-9986
(615) 532-1998 (fax)
✉ jlewis@mail.state.tn.us
http://www.state.tn.us/mental/ttap.html

TEXAS

TEXAS ASSISTIVE TECHNOLOGY PARTNERSHIP
University of Texas at Austin
Texas Univ. Affiliated Program
SZB252-D5100
Austin, TX 78712-1290
(800) 828-7839
(512) 471-1844 (TTY)
(512) 471-7549 (fax)
✉ s.elrod@mail.utexas.edu
http://tatp.edb.utexas.edu

VIRGIN ISLANDS

U.S. VIRGIN ISLAND TECHNOLOGY-RELATED ASSISTANCE FOR INDIVIDUALS WITH DISABILITIES (TRAID)
University of the Virgin Islands/UAP
#2 John Brewers Bay
St. Thomas, VI 00801-0990
(340) 693-1323
(340) 693-1325 (fax)
✉ yhabtes@ uvi.edu
http://www.uvi.edu/pub-relations/viuapindex.html

UTAH

UTAH ASSISTIVE TECHNOLOGY PROGRAM
Center for Persons with Disabilities
6588 Old Main Hill
Logan, UT 84322-6588
(435) 797-3886
(435) 797-1981 (V/TTY)
(435) 797-2355 (fax)
✉ marty@cpd2.usu.edu
http://www.uatp.usu.edu

VERMONT

VERMONT ASSISTIVE TECHNOLOGY PROJECT
103 South Main Street
Weeks Building, First Floor
Waterbury, VT 05671-2305
(802) 241-2620 (V/TTY)
(802) 241-2174 (fax)
✉ lynnec@dad.state.vt.us
http://www.dad.state.vt.us/atp

VIRGINIA

VIRGINIA ASSISTIVE TECHNOLOGY SYSTEM
8004 Franklin Farms Drive
Richmond, VA 23288-0300
(800) 435-8490
(804) 662-9990 (V/TTY)
(804) 662-9478 (fax)
✉ vatskhk@aol.com
http://www.vats.org

WASHINGTON

WASHINGTON ASSISTIVE TECHNOLOGY ALLIANCE
Univ. of Washington
Box 357920
Seattle, WA 98195-7920
(800) 214-8731 (V/TTY)
✉ uwat@u.washington.edu
Homepage: http://www.wata.org

WEST VIRGINIA

WEST VIRGINIA ASSISTIVE TECHNOLOGY SYSTEM
University Affiliated Center for Developmental Disabilities
Airport Research and Office Park
955 Hartman Run Road
Morgantown, WV 26505
(304) 293-4692 (V/TTY)
(800) 841-8436 (In-State)
(304) 293-7294 (fax)
✉ jstewart@wvu.edu
http://www.wvu.edu/~uacdd/wvats/wvats.htm

WISCONSIN

WISTECH
Wisconsin Assistive Technology Program
Division of Supportive Living
PO Box 7851
1 W. Wilson Street, Rm. 450
Madison, WI 53707
(608) 266-9303
(608) 267-3203 (fax)
(608) 267-9880 (TTY)
✉ drennvi@dhfs.state.wi.us
http://www.dhfs.state.wi.us/Aging/wistech/wistech.htm

WYOMING

WYOMING'S NEW OPTIONS IN TECHNOLOGY (WYNOT)
University of Wyoming
1465 North 4th Street, Suite 111
Laramie, WY 82072
(307) 766-2095
307) 766-2084 (V/TTY)
(307) 721-2084 (fax)
✉ wynot.uw@uwyo.edu
✉ mmassie@uwyo.edu
http://wind.uwyo.edu/wynot/wynot.htm

Assistive Technology Consortium

The NJ Consortium to Access-Abilities provides a non-competitive network of communication and support for:

- teachers,
- students, and
- families.

The Consortium also serves as a resource which provides services in

- assistive computer technology and
- augmentative communication.

The following list contains the names, areas of expertise, and e-mail addresses of consortium members. E-mails are indicated by the symbol, ✉. Parents can contact any of these individuals for more information on services in assistive computer technology and augmentative communication.

The NJ Consortium to Access-Abilities is hosting a conference in March, 2000. See *Exceptional Parent* February 2000 for more details.

William Paterson University College of Education
Department of Special Education and Counseling, Assistive technology Center: Dr. Denise Stone
✉stoned@WPUNJ.edu

Bergen County Special Services
Center for Assistive Technology: Mrs. Cathy Tamburello, Coordinator:
✉cattan@bergen.org

Promedia, Inc.
Software and Hardware Vendor and On-Site Trainer
✉Tom@PromediaNJ. com

Abilitech Pam Brillante
✉pambrillante@aol.com

NJ CART John Noecker
✉jnoecker@worldnet.att.net

MAC and MAC Adaptations Dave Weller
✉Dave9969@mindspring.com

Cerebral Palsy Association of Middlesex
Travis Tallman
✉ttennis@hotmail.com

United Cerebral Palsy of New Jersey
Fred Tchang
✉ftchang@ucpanj.org

Pennsylvania Initiative on Assistive Technology
Amy Goldman
✉amygolden@astroltemple.edu

The College of New Jersey
NJ Tech Newsletter
Dr. Amy Dell
✉dellamy@dtcnj.edu

WPUNJ Americans With Disabilities
Campus Coordinator
Janet Barone DeSenza
✉desenzo@wpunj.edu

Passaic County Vocational Technical High School
AT Lab
Josephine Bono
✉jbono@pcti.tec.nj.us

Recordings for the Blind and Dyslexic
Ann Marie Cook
✉acooke@RFBD.org

Center for Enabling Technology Assessments and Workshops
Theresa Lupo
✉centnj@aol.com>

TECH Connection
Joanne Castellano
✉TecConn@aol.com

The New Jersey Consortium to Access-Abilities Web site is http://www.wpunj.edu/coe/resources/asstech.

NOTES:

Adaptive Recreation Organization

This directory includes national organizations offering adaptive sports and recreational activities for people of many abilities. In addition to providing a variety of opportunities for fun and social interaction, some of the listed organizations offer support groups as well. Most of the organizations have local chapters, or they can do referrals to other local organizations which offer similar activities.

USING THIS DIRECTORY
A description of services provided by individual groups follows each listing in this directory. Numbers correspond to items listed in the **Key to Services**. When available, World Wide Web sites and e-mail addresses have been included. Web sites are listed with the standard **http://** before each. E-mail addresses are indicated by the symbol, ✉. (Unless otherwise indicated, all telephone numbers are for voice only.)

AIM for the Handicapped (Adventures in Movement for the Handicapped)
945 Danbury Rd.
Dayton, OH 45420
(800) 332-8210
(937) 294-4611
(937) 294-3783 (fax)
✉aimkids@siscom.net
1,2,4

American Amputee Foundation, Inc.
PO Box 250218
Little Rock, AR 72225
(501) 666-2523
(501) 666-8367 (fax)
1,2,4,7,8,9

American Association for Health, Physical Education, Recreation, and Dance
1900 Association Dr.
Reston, VA 20191-1599
(800) 213-7193
(703) 476-3400
(703) 476-9527 (fax)
✉aalr@aahperd.org
http://www.aahperd.org/aalr.html
1,2,3,6,7,9

American Blind Bowling Association
315 N. Main St.
Houston, PA 15342
(412) 745-5986

American Blind Skiing Foundation
610 S. William St.
Mt. Prospect, IL 60056
(847) 255-1739

American Camping Association
5000 State Rd 67 N
Martinsville, IN 46151-7902
(800) 428-2267
(765) 342-8456
(765) 342-2065
(765) 342-2065 (fax)
✉bookstore@aca-campus.org
http://www.acacamps.org
1,2

American Cancer Society
Home Office
1599 Clifton Rd. NE
Atlanta, GA 30329-4251
(800) 227-2345
http://www.cancer.org

American Canoe Association
7432 Alban Station Blvd., Ste B-232
Springfield, VA 22150
(703) 451-0141
(703) 451-2245 (fax)
✉acadirect@aol.com
http://www.aca-paddler.org
1,2,6

American Sled Hockey Association
10933 Johnson Ave. S.
Bloomington, MN 55437
(612) 888-5331
✉anschotzln@aol.com

American Wheelchair Table Tennis Association
23 Parker St.
Port Chester, NY 10573
(914) 937-3932 (phone/fax)
1,2

American Red Cross
National Headquarters
8111 Gatehouse Rd.
Falls Church, VA 22042
(703) 206-6000
http://www.redcross.org

Beneficial Designs, Inc.
P.O. Box 8317
Santa Cruz, CA 95060
(831) 429-8447
(831) 423-8450 (fax)
✉mail@beneficialdesigns.com
1; designs adaptive sporting equipment

Boy Scouts of America
1325 W. Walnut Hill Ln.
Irving, TX 75038
(972) 580-2000
(972) 580-2502 (fax)
http://www.bsd.scouting.org

Breckenridge Outdoor
Education Center
PO Box 697
Breckenridge, CO 80424
(800) 383-2632
(972) 453-6422
(970) 453-4676 (fax)
✉http://www.boec@boec.org
1,2

Department of Recreation
CB#3185
730 Airport Rd. UNC
Chapel Hill, NC 27599-3185
(919) 962-0534
(919) 962-1223 (fax)
✉kluken@email.unc.edu
2

Cooperative Wilderness Handicapped Outdoor Group (C.W. HOG)
PO Box 8128
Pocatello, ID 83209
(208) 236-3912
(208) 236-4600 (fax)
✉branjeff@isu.edu
http://www.isu.edu/cwhog/
1,2,4

Courage Center
3915 Golden Valley Rd.
Golden Valley, MN 55422
(612) 588-0811
(612) 520-0577 (fax)
✉sports@courage.com
http://freenet.msp.mn.us/ip/health/courage_center/top.html

Department of the Interior
Accessibility Management Program
PO Box 37127
Washington, DC 20013
(202) 208-3100
(202) 343-3674 (fax)
✉david_park@nps.gov

Disabled Sports USA
451 Hungerford Dr., Ste. 100
Rockville, MD 20850
(301) 217-0960
(301) 217-0968 (fax)
✉dsusa@dsusa.org
1,4,5

The 52 Association for the Handicapped, Inc.
350 5th Ave., Ste. 3304
New York, NY 10118-0069
(212) 868-1217
(212) 868-1219 (fax)

Freedom's Wings International
1832 Lake Ave.
Scotch Plains, NJ 07076
(908) 232-6354
✉raydt@earthlink.net
http://www.freedomswings.com

Girl Scouts of the USA
Membership and Program Group
420 5th Ave.
New York, NY 10018
(800) 223-0624
(212) 852-8000
(212) 852-6515 (fax)
http://www.gsusa.org

Handicapped Scuba Association
1104 El Prado
San Clemente, CA 92672-4637
(800) 673-5084
(949) 498-6128
✉hsahdq@compuserve.com
1,2,4

Houston Challengers
TIRR Sports
1475 West Gray, Ste. 166
Houston, TX 77018-4926
(713) 521-3737

International Wheelchair Aviators
1117 Rising Hill Way
Escondido, CA 92029
1; provides information for pilots or future pilots who have a disability.

National Ability Center (NAC)
P.O.Box 682799
Park City, UT 84068-2799
(435) 649-3991 (voice/TDD)
(435) 658-3992 (fax)
✉nac@xmission.com
http://www.nationalabilitiescenter.org

National Amputee Golf Association
PO Box 23285
Milwaukee, WI 53223-0285
(800) 633-6242
(414) 376-1268
✉naga@execpc.com
1,2,3,4,6,7

National Archery Association
One Olympic Plaza
Colorado Springs, CO 80909
(719) 578-4576
(719) 632-4733 (fax)
http://www.isarchery.org
1,2,4,5,6

National Center on Accessibility
University of Indiana
5020 State Rd. 67 N.
Martinsville, IN 46151
(765) 349-9240
(765) 342-6658 (fax)
✉nca@indiana.edu
http://www.indiana.edu~tildanca

National Foundation of Wheelchair Tennis
940 Calle Amanecer, Ste. B
San Clemente, CA 92673
(714) 361-6603 (fax)
✉nfwt@aol.com
1,2,4,5,6,7

Disabled Sports USA
451 Hungerford Dr., Ste. 100
Rockville, MD 20850
(301) 217-0960
(301) 217-0963
(301) 217-0968 (fax)
✉dsusa@dsusa.org

National Recreation and Park Association
22377 Belmont Ridge Rd.
Ashburn, VA 20148
(703) 858-0784
✉info@nrpa.org
http://www.nrpa.org

NRA Disabled Shooting Services
National Rifle Association of America
11250 Waples Mill Rd.
Fairfax, VA 22030
(703) 267-1000
http://www.nra.org

National Skeet & Sporting Clay Headquarters
5931 Roft Rd.
San Antonio, TX 78253
(210) 688-3014 (fax)
http://www.nssa-nsta.com

National Wheelchair Shooting Federation
102 Park Ave.
Rockledge, PA 19046
(215) 379-2359
(215) 663-0102 (fax)

National Wheelchair Softball Association
1616 Todd Ct.
Hastings, MN 55033
(651) 437-1792
(651) 437-3889 (fax)
http://www.wheelchairsoftball.com

North American Riding for the Handicapped Association (NARHA)
PO Box 33150
Denver, CO 80233
(800) 369-7433
(303) 452-1212
(303) 252-4610 (fax)
✉narha@fril.com

Paralyzed Veterans of America
801 Eighteenth St. NW
Washington, DC 20006
(800) 424-8200
(202) 872-1300
http://www.pva.org

Ski for Light, Inc.
5 McAuliffe Dr.
North Brunswick, NJ 08902
(609) 520-8079
✉acooke@rfbd.org

Special Olympics International
1325 G St. NW, Ste. 500
Washington, DC 20005
(202) 628-3630
(202) 824-0200 (fax)
✉soimail@aol.com
http://specialolympics.org

SIRC (Sport Information Resource Center)
1600 James Naismith Dr., Ste. 107
Gloucester Ontario, Canada K1B 5N4
(613) 748-5658
(613) 748-5701 (fax)
✉ref@sirc.ca
http://www.sportguest.com
http://circ.ca
sports database for professionals only.

United States Cerebral Palsy Athletic Association
25 W. Independence Way
Kingston, Rhode Island 02881
(481) 874-7465
(481) 874-7468 (fax)

USA Deaf Sports Federation
3607 Washington Boulevard, Ste. 4
Ogden, UT 84403-1737
(800) 393-8710 (voice)
(801) 393-7916 (TTY)
(801) 393-2263 (fax)
✉deafsports@juno.com
1,2,5

US Association of Blind Athletes (USABA)
33 N. Institute St.
Colorado Springs, CO 80903
(719) 630-0422
(719) 630-0616 (fax)
✉usainfa@iex.net
http://www.usaba.org
1,2,4,5,6,9

US Blind Golfers Association
3094 Shamrock St. N.
Tallahassee, FL 32308
(904) 893-4511(voice/fax)
✉nightgolf@concentric.net
1,2

KEY TO SERVICES

1 Periodical/newsletter
2 Informational materials
3 Networking/matching
4 Referrals to local resources
5 Local chapters
6 National conferences
7 National advocacy efforts
8 Fund research
9 Maintain research registry

Adaptive Recreation Organization

US Cerebral Palsy Athletic Association
200 Harrison Ave.
Newport, RI 02840
(401) 848-2460
(401) 848-5280 (fax)
✉uscpaa@mail.bbsnet.com
1,2,3,4,6

US Disabled Ski Team
PO Box 100
Park City, UT 84060
(435) 649-9090
(435) 649-3613 (fax)
✉info@ussa.org
http://www.usskiteam.org

US Rowing Association
201 S. Capitol Ave, Ste 400
Indianapolis, IN 46225
(317) 237-5656
(317) 237-5646 (fax)
✉members@usrowing.org
http://www.usrowing.org

US Wheelchair Weightlifting Association
39 Michael Pl.
Levittown, PA 19057
(215) 945-1964
(215) 946-2574 (fax)
1,3

VISIONS/Vacation Camp for the Blind
500 Greenwich St., 3rd Fl.
New York, NY 10013
(212) 625-1616
(212) 219-4078 (fax)
✉visions@sprintmail.com
http://www.visionsvcb.org
3

Vinland Center
PO Box 308
3675 Ihduhapi Rd.
Loretto, MN 55357
(612) 479-3555
(612) 479-2605 (fax)
✉vinland@vinlandcenter.org

Voyageur Outward Bound School
111 Third Ave. S., Ste. 120
Minneapolis, MN 55401-2551
(800) 328-2943
(612) 338-0131
(612) 338-3540 (fax)
✉vobs@vobs.com

Wilderness Inquiry
1313-5th St. SE., Box 84
Minneapolis, MN 55414-1546
(800) 728-0719 (voice/TTY)
(612) 379-3858
(612) 379-5972 (fax)
✉info@wildernessinquiry.org

Wilderness On Wheels Foundation
3131 S. Vaughn Way, #305
Aurora, CO 80014
(303) 751-3959
1,2,4,7

NOTES:

NFADB

National Family Association for Deaf-Blind
is a non-profit, volunteer-based family association. Our philosophy is that *individuals who are deaf-blind are valued members of society and are entitled to the same opportunities and choices as other members of the community.*

NFADB is the largest national network of families focusing on issues surrounding deaf-blindness. Using a team of eleven Regional Directors and an Executive Committee, we advocate for all persons who are deaf-blind of any age and cognitive ability. We publish a tri-annual newsletter; support national policies to benefit people who are deaf-blind; collaborate with professionals; work with national projects; and maintain a website with a chatroom and listserv for members.

For more information or to contact your Regional Director:

NFADB
111 Middle Neck Road
Sands Point NY 11050
1-800-255-0411 ext 275
NFADB@aol.com
www.NFADB.ORG

Ralph Warner, **President**
Peg Pedersen, **Vice President**
Pat McCallum, **Secretary**
Linda Syler, **Treasurer**

Region 1 CT MA ME NH RI VT
Region 2 NJ NY PR VI
Region 3 DC DE MD PA VA WV
Region 4A AL FL GA MS
Region 4B KY NC SC TN
Region 5 IL IN OH MI MN WI
Region 6 AR LA NM OK TX
Region 7 IA KS MO NE
Region 8 CO MT ND SD UT WY
Region 9 AZ CA HI NV
Region 10 AK ID OR WA

NFADB is supported in part by the Helen Keller National Center, Sands Point, NY and the Hilton/Perkins Program of Perkins School for the Blind, Watertown, MA. The Hilton/Perkins Program is funded by a grant from the Conrad N. Hilton Foundation of Reno, Nevada.

Circle #93

NEW ENGLAND PEDIATRIC CARE

78 Boston Road
No. Billerica, MA
01862
978-667-5123

New England Pediatric Care
is an 80 bed pediatric skilled nursing facility which provides long-term care, sub-acute, rehabilitation services and a private special education day school. The facility is affiliated with New England Medical Center and benefits from all its clinical resources. It is specially designed for children from birth to age 22 who are medically complex and have severe cognitive and neurological impairments.

•SKILLED NURSING CARE•
•REHABILITATION SERVICES•
•COMPREHENSIVE MEDICAL SERVICES•
•THERAPEUTIC RECREATION•
•SOCIAL WORK SERVICES•
•CHAPTER 766-PRIVATE DAY SCHOOL•

•EXTENDED ADMISSIONS•
•SUB-ACUTE ADMISSIONS•
•RESPITE SERVICES•

Accredited by Joint Commission on Accreditation of Healthcare Organizations

Circle #95

Children's Hospitals

The National Association of Children's Hospitals and Related Institutions is a national organization of children's hospitals and represents hospitals in the United States, Canada, Mexico, Puerto Rico, and Singapore. NACHRI promotes the health and well-being of children and their families through support of children's hospitals and health systems that are committed to excellence in providing healthcare to children. It does so through education, research, health promotion, and advocacy. NACHRI's 161 member institutions work to ensure children's access to healthcare and the continuing ability of children's hospitals to provide services needed by children.

This listing includes NACHRI **members**, **associates**, and **supporters**. NACHRI members comprise freestanding children's hospitals, children's hospitals within hospitals, and specialty hospitals. The **specialty** children's hospitals provide clinical specialization in • orthopedics, • rehabilitation, • chronic diseases, or • psychiatry. One of the specialty hospitals, Texas Scottish Rite Hospital for Children in Dallas, Texas is supported by private donations and does not bill for services. The hospital specializes in pediatric orthopedics and learning disabilities and treats children who meet its Texas residency requirements. • A group comprised of 22 **Shriners children's hospitals** is also a NACHRI member; these hospitals specialize in orthopedics and burn treatment and provide their very expensive treatments free of charge.

For more information about NACHRI children's hospitals, visit the NACHRI Web site at http://www.childrenshospitals.net/nachri. Direct links are available to most members listed under "About NACHR." For more information about NACHRI contact member services at NACHRI, 401 Wythe Street, Alexandria, VA 22314; telephone: (703) 684-1355; fax: (703) 684-1589; e-mail: lbaldwin@nachri.org.

MEMBER HOSPITALS

ALABAMA

The Children's Hospital of Alabama
Birmingham, AL
Tel: (205) 939-9100

University of South Alabama Children's and Women's Hospital
Mobile, AL
Tel: (334) 415-1000

ARKANSAS

Arkansas Children's Hospital
Little Rock, AR
Tel: (501) 320-1100

ARIZONA

Phoenix Children's Hospital
Phoenix, AZ
Tel: (602) 239-5920

CALIFORNIA

Loma Linda University Children's Hospital
Loma Linda, CA
Tel:(909) 558-8111

Mattel Children's Hospital at UCLA
Los Angeles, CA
Tel: (310) 825-4125

Childrens Hospital Los Angeles
Los Angeles, CA
Tel: (323) 669-2450

Valley Children's Hospital
Madera, CA
Tel: (559) 353-5185

Children's Hospital Oakland
Oakland, CA
Tel: (510) 428-3000

Children's Hospital of Orange County
Orange, CA
Tel: (714) 997-3000

Lucile Packard Children's Health Services
Palo Alto, CA
Tel: (650) 497-8000

University Children's Hospital - University of California - Davis Medical Center
Sacramento, CA
Tel: (916) 734-2011

Children's Hospital and Health Center
San Diego, CA
Tel: (619) 576-1700

COLORADO

The Children's Hospital
Denver, CO
Tel: (303) 861-8888

CONNECTICUT

Connecticut Children's Medical Center
Hartford, CT
Tel: (860) 545-9000

Yale - New Haven Hospital
New Haven, CT
Tel: (203) 688-4242

DELAWARE

Alfred I. duPont Hospital for Children
Wilmington, DE
Tel: (302) 651-4000

DISTRICT OF COLUMBIA

Children's National Medical Center
Washington, DC
Tel: (202) 884-5000

FLORIDA

Shands Children's Hospital at the University of Florida
Gainesville, FL
Tel: (352) 395-0111

Wolfson Children's Hospital
Jacksonville, FL
Tel: (904) 202-2000

Miami Children's Hospital
Miami, FL
Tel: (305) 666-6511

All Children's Hospital, Inc.
St. Petersburg, FL
Tel: (727) 898-7451

GEORGIA

Children's Healthcare of Atlanta
Atlanta, GA
Tel: (404) 256-5252

Hughes Spalding Children's Hospital
Atlanta, GA
Tel: (404) 616-6192

Children's Medical Center - Medical College of Georgia
Augusta, GA
Tel: (706) 721-0211

The Children's Hospital at the Medical Center of Central Georgia
Macon, GA
Tel: (912) 633-1104

IOWA

Children's Hospital of Iowa at the University of Iowa Hospitals and Clinics
Iowa City, IA
Tel: (319) 356-2799

ILLINOIS

The University of Chicago Children's Hospital
Chicago, IL
Tel: (773) 702-6239

The Children's Memorial Hospital
Chicago, IL
Tel: (773) 880-4000

Ronald McDonald Children's Hospital of Loyola University Medical Center
Maywood, IL
Tel: (708) 216-4798

Children's Hospital of Illinois at Saint Francis Medical Center
Peoria, IL
Tel: (309) 655-3722

INDIANAPOLIS

James Whitcomb Riley Hospital for Children Clarian Health
Indianapolis, IN
Tel: (317) 274-5000

KENTUCKY

University of Kentucky Children's Hospital
Lexington, KY
Tel: (606) 323-6000

Kosair Children's Hospital - Alliant Health System
Louisville, KY
Tel: (502) 629-6000

LOUISIANA

Children's Hospital
New Orleans, LA
Tel: (504) 899-9511

Louisiana State University Medical Center - Shreveport
Shreveport, LA
Tel: (318) 675-5000

MAINE

The Barbara Bush Children's Hospital at Maine Medical Center
Portland, ME
Tel: (207) 871-0111

MARYLAND

Johns Hopkins Children's Center
Baltimore, MD
Tel: (410) 955-5000

Maryland's Hospital for Children
Baltimore, MD
Tel: (410) 328-6777

MASSACHUSETTS

Floating Hospital for Children at New England Medical Center
Boston, MA
Tel: (617) 636-5000

Children's Hospital
Boston, MA
Tel: (617) 355-6000

MICHIGAN

C. S. Mott Children's Hospital - University of Michigan Hospitals
Ann Arbor, MI
Tel: (734) 936-5514

Children's Hospital of Michigan
Detroit, MI
Tel: (313) 745-5437

MINNESOTA

Children's Hospitals and Clinics - Minneapolis
Minneapolis, MN
Tel: (612) 813-6100

Mayo Eugenio Litta Children's Hospital - Mayo Medical Center
Rochester, MN
Tel: (507) 284-2511

Children's Hospitals and Clinics - St. Paul
St. Paul, MN
Tel: (651) 220-6110

MISSOURI

Children's Hospital at University Hospital and Clinics
Columbia, MO
Tel: (573) 882-4141

The Children's Mercy Hospital
Kansas City, MO
Tel: (816) 234-3000

Cardinal Glennon Children's Hospital
St. Louis, MO
Tel: (314) 577-5600

St. Louis Children's Hospital
St. Louis, MO
Tel: (314) 454-6000

NORTH DAKOTA

Merit Care Children's Hospital
Fargo, ND
Tel: (701) 234-6000

NEBRASKA

Children's Hospital
Omaha, NE
Tel: (402) 354-5400

NEW HAMPSHIRE

Dartmouth-Hitchcock Medical Center - Children's Hospital at Dartmouth
Lebanon, NH
Tel: (603) 650-5000

NEW JERSEY

The Children's Regional Hospital at Cooper Hospital/University Medical Center
Camden, NJ
Tel: (609) 342-2000

Hackensack University Medical Center
Hackensack, NJ
Tel: (201) 996-2000

Robert Wood Johnson University Hospital
New Brunswick, NJ
Tel: (732) 828-3000

UMDNJ - University Hospital
Newark, NJ
Tel: (973) 972-5658

Children's Hospital of New Jersey at Newark Beth Israel Medical Center
Newark, NJ
Tel: (973) 926-7583

NEW YORK

Schneider Children's Hospital - Long Island Jewish Medical Center
New Hyde Park, NY
Tel: (718) 470-3000

Babies & Children's Hospital of New York
New York, NY
Tel: 212) 305-2500

Children's Hospital at Westchester Medical Center
Valhalla, NY
Tel: (914) 493-7000

OHIO

Children's Hospital Medical Center of Akron
Akron, OH
Tel: (330) 379-8200

Children's Hospital Medical Center
Cincinnati, OH
Tel: (513) 636-4200

Rainbow Babies and Children's Hospital
Cleveland, OH
Tel: (216) 844-3762

Children's Hospitals

Children's Hospital
Columbus, OH
Tel: (614) 722-2000

The Children's Medical Center
Dayton, OH
Tel: (937) 226-8300

Toledo Children's Hospital
Toledo, OH
Tel: (419) 471-4000

Mercy Children's Hospital at St. Vincent Mercy Medical Center
Toledo, OH
Tel: (419) 251-4180

Western Reserve Care System - Tod Children's Hospital
Youngstown, OH
Tel: (330) 740-3898

OKLAHOMA

The Children's Hospital at Saint Francis
Tulsa, OK
Tel: (918) 494-2200

OREGON

Doernbecher Children's Hospital at the Oregon Health Sciences University
Portland, OR
Tel: (503) 418-5195

PENNSYLVANIA

The Children's Hospital of Philadelphia
Philadelphia, PA
Tel: (215) 590-1000

Temple University Children's Medical Center
Philadelphia, PA
Tel: (215) 707-6100

Children's Hospital of Pittsburgh
Pittsburgh, PA
Tel: (412) 692-5325

RHODE ISLAND

Hasbro Children's Hospital at Rhode Island Hospital
Providence, RI
Tel: (401) 444-8984

SOUTH CAROLINA

The Children's Hospital Medical University of South Carolina
Charleston, SC
Tel: (843) 876-2123

Children's Hospital of Palmetto Richland
Columbia, SC
Tel: (803) 434-4676

TENNESSEE

Children's Hospital at Johnson City Medical Center
Johnson City, TN
Tel: (423) 431-6111

East Tennessee Children's Hospital
Knoxville, TN
Tel: (423) 541-8000

Le Bonheur Children's Medical Center, Inc.
Memphis, TN
Tel: (901) 572-3000

St. Jude Children's Research Hospital
Memphis, TN
Tel: (901) 495-3300

Vanderbilt Children's Hospital
Nashville, TN
Tel: (615) 322-5000

TEXAS

Children's Hospital of Austin
Austin, TX
Tel: (512) 324-1000

Driscoll Children's Hospital
Corpus Christi, TX
Tel: (512) 694-5000

Children's Medical Center of Dallas
Dallas, TX
Tel: (214) 456-7000

Cook Children's Medical Center
Fort Worth, TX
Tel: (817) 885-4000

Children's Hospital at the University of Texas Medical Branch Hospitals
Galveston, TX
Tel: (409) 772-3460

Texas Children's Hospital
Houston, TX
Tel: (713) 770-1000

Covenant Children's Hospital
Lubbock, TX
Tel: (806) 784-5040

Christus Santa Rosa Children's Hospital
San Antonio, TX
Tel: (210) 704-2011

UTAH

Primary Children's Medical Center
Salt Lake City, UT
Tel: (801) 588-2000

VIRGINA

University of Virginia Children's Medical Center
Charlottesville, VA
Tel: (804) 924-9821

Inova Fairfax Hospital for Children
Falls Church, VA
Tel: (703) 204-6008

Children's Hospital of The King's Daughters Health System
Norfolk, VA
Tel: (757) 668-7000

VERMONT

Fletcher Allen Health Care
Burlington, VT
Tel: (802) 656-2345

WASHINGTON

Children's Hospital & Regional Medical Center
Seattle, WA
Tel: (206) 526-2000

WEST VIRGINIA

Charleston Area Medical Center - Women and Children's Hospital
Charleston, WV
Tel: (304) 348-2752

WISCONSIN

University of Wisconsin Children's Hospital
Madison, WI
Tel: (608) 263-6400

Children's Hospital of Wisconsin
Milwaukee, WI
Tel: (414) 266-2000

CANADA

Children's & Women's Health Centre of British Columbia
Vancouver, BC CANADA
Tel: (604) 875-3750

Children's Hospital of Eastern Ontario
Ottawa, ON CANADA
Tel: (613) 737-2200

The Hospital for Sick Children
Toronto, ON CANADA
Tel: (416) 813-1500

SPECIALTY HOSPITALS

DISTRICT OF COLUMBIA

The Hospital for Sick Children
Washington, DC
Tel: (202) 832-4400

FLORIDA

Shriners Hospitals for Children (Corporate Office)
Tampa, FL
Tel: (813) 281-8450

ILLINOIS

La Rabida Children's Hospital and Research Center
Chicago, IL
(773) 363-6700

INDIANA

St. Vincent Children's Specialty Hospital
Indianapolis, IN
Tel: (317) 415-5500

MARYLAND

Kennedy Krieger Children's Hospital
Baltimore, MD
Tel: (410) 502-9000

Mt. Washington Pediatric Hospital, Inc.
Baltimore, MD
Tel: (410) 578-8600

MINNESOTA

Gillette Children's Specialty Healthcare
St. Paul, MN
Tel: (651) 229-3838

MONTANA

Shodair Hospital
Helena, MT
Tel: (406) 444-7500

NEW JERSEY

Children's Specialized Hospital
Mountainside, NJ
Tel: (908) 233-3720

NEW MEXICO

Carrie Tingley Hospital
Albuquerque, NM
Tel: (505) 272-5200

NEW YORK

St. Mary's Hospital for Children
Bayside, NY
Tel: (718) 281-8800

Blythedale Children's Hospital
Valhalla, NY
Tel: (914) 592-7555

OHIO

Cleveland Clinic Children's Hospital for Rehabilitation
Cleveland, OH
Tel: (216) 721-5400

OKLAHOMA

Children's Medical Center
Tulsa, OK
Tel: (918) 664-6600

PENNSYLVANIA

The Children's Institute
Pittsburgh, PA
Tel: (412) 420-2400

TEXAS

Texas Scottish Rite Hospital for Children
Dallas, TX
Tel: (214) 559-5000

Our Children's House at Baylor
Dallas, TX
Tel: (214) 820-9800

VIRGINIA

Children's Hospital
Richmond, VA
Tel: (804) 321-7474

ASSOCIATES

ARIZONA

Children's Health Center - St. Joseph's Hospital
Phoenix, AZ
Tel: (602) 285-3000

FLORIDA

Joe DiMaggio Children's Hospital at Memorial Regional Hospital
Hollywood, FL
Tel: (954) 987-2000

Arnold Palmer Hospital for Children & Women Orlando Regional Healthcare System
Orlando, FL
Tel: (407) 649-6960

Tampa General Healthcare/ Children's Medical Center
Tampa, FL
Tel: (813) 251-7000

IOWA

Raymond Blank Memorial Hospital for Children
Des Moines, IA
Tel: (515) 241-6602

MASSACHUSETTS

Baystate Medical Center Children's Hospital
Springfield, MA
Tel: (413) 784-0000

MICHIGAN

Henry Ford Hospital
Detroit, MI
Tel: (313) 916-2600

De Vos Children's Hospital
Grand Rapids, MI
Tel: (616) 391-1898

Bronson Methodist Hospital
Kalamazoo, MI
Tel: (616) 341-8820

Sparrow Regional Children's Center - Sparrow Hospital & Health System
Lansing, MI
Tel: (517) 483-2700

NEW JERSEY

St. Joseph's Children's Hospital
Paterson, NJ
Tel: (973) 754-2505

NEW YORK

Crouse Hospital, Inc.
Syracuse, NY
Tel: (315) 470-7111

NORTH CAROLINA

North Carolina Children's Hospital - University of North Carolina Hospitals
Chapel Hill, NC
Tel: (919) 966-4131

Carolinas Medical Center
Charlotte, NC
Tel: (704) 355-2000

Children's Hospital - University Health Systems of Eastern North Carolina
Greenville, NC
Tel: (252) 816-4100

OHIO

Cleveland Clinic Children's Hospital
Cleveland, OH
Tel: (216) 444-2200

OREGON

Legacy Emanuel Children's Hospital
Portland, OR
Tel: (503) 413-2500

PENNSYLVANIA

Janet Weis Children's Hospital at Geisinger
Danville, PA
Tel: (717) 271-6211

SOUTH CAROLINA

Children's Hospital of the Greenville Hospital System
Greenville, SC
Tel: (864) 558-8860

TEXAS

Hermann Children's Hospital
Houston, TX
Tel: (713) 704-4000

CANADA

Children's Health Centre of Northern Alberta
Edmonton, AB CANADA
Tel: (780) 407-8655

SINGAPORE

KK Women's and Children's Hospital
SINGAPORE
Tel: 011-65-293-4044

SUPPORTERS

COLORADO

The Hospital for Infants & Children at Presbyterian/St. Luke's Medical Center
Denver, CO
Tel: (303) 839-6000

FLORIDA

Broward General Medical Center
Fort Lauderdale, FL
Tel: (954) 355-5800

Lee Memorial Health System
Fort Myers, FL
Tel: (941) 432-3215

Nemours Children's Clinic - Jacksonville
Jacksonville, FL
Tel: (904) 390-3600

Baptist Children's Hospital
Miami, FL
Tel: (305) 596-6503

Tampa Children's Hospital at St. Joseph's
Tampa, FL
Tel: (813) 870-4662

The Richard and Pat Johnson Children's Hospital at St. Mary's Medical Center
West Palm Beach, FL
Tel: (954) 844-6300

GEORGIA

George and Marie Backus Children's Hospital at Memorial Medical Center
Savannah, GA
Tel: (912) 350-8000

IDAHO

St. Luke's Regional Medical Center
Boise, ID
Tel: (208) 381-2116

NEVADA

Sunrise Children's Hospital
Las Vegas, NV
Tel: (702) 731-8000

NEW JERSEY

Voorhees Pediatric Facility
Voorhees, NJ
Tel: (609) 346-3300

NORTH CAROLINA

Ruth & Billy Graham Children's Health Ctr. at Mission St. Joseph's
Asheville, NC
Tel: (828) 254-4701

Cape Fear Valley Medical Center - Cumberland County Hospital System
Fayetteville, NC
Tel: (910) 609-4000

OKLAHOMA

Children's Hospital of Oklahoma - The University Hospital
Oklahoma City, OK
Tel: (405) 271-6165

PENNSYLVANIA

St. Christopher's Hospital for Children
Philadelphia, PA
Tel: (215) 427-5000

TEXAS

North Texas Hospital for Children at Medical City Dallas
Dallas, TX
Tel: (972) 566-7885

WASHINGTON

MultiCare Medical Center/Mary Bridge Children's Hospital and Health Center
Tacoma, WA
Tel: (253) 552-1000

PUERTO RICO

San Jorge Children's Hospital
Santurce, PUERTO RICO
Tel: (787) 727-1000

CANADA

Children's Hospital at Hamilton Health Sciences Corporation
Hamilton, ON CANADA
Tel: (905) 521-2100

SHRINERS HOSPITALS

CALIFORNIA

Shriners Hospitals for Children - Los Angeles
Los Angeles, CA
Tel: (213) 388-3151

Sacramento Shriners Hospital
Sacramento, CA
Tel: (916) 453-2000

FLORIDA

Tampa Shriners Hospital
Tampa, FL
Tel: (813) 972-2250

HAWAII

Honolulu Shriners Hospital
Honolulu, HI
Tel: (808) 941-4466

ILLINOIS

Chicago Shriners Hospital
Chicago, IL
Tel: (773) 622-5400

KENTUCKY

Lexington Shriners Hospital
Lexington, KY
Tel: (606) 266-2101

LOUISIANA

Shreveport Shriners Hospital
Shreveport, LA
Tel: (318) 222-5704

MASSACHUSETTS

Boston Shriners Hospital
Boston, MA
Tel: (617) 722-3000

Springfield Shriners Hospital
Springfield, MA
Tel: (413) 787-2000

MINNESOTA

Twin Cities Shriners Hospital
Minneapolis, MN
Tel: (612) 335-5300

MISSOURI

St. Louis Shriners Hospital
Saint Louis, MO
Tel: (314) 432-3600

OHIO

Cincinnati Shriners Hospital
Cincinnati, OH
Tel: (513) 872-6000

OREGON

Portland Shriners Hospital
Portland, OR
Tel: (503) 241-5090

PENNSYLVANIA

Erie Shriners Hospital
Erie, PA
Tel: (814) 875-8700

Philadelphia Shriners Hospital
Philadelphia, PA
Tel: (215) 430-4000

SOUTH CAROLINA

Greenville Shriners Hospital
Greenville, SC
Tel: (864) 271-3444

TEXAS

Galveston Shriners Hospital
Galveston, TX
Tel: (409) 770-6600

Houston Shriners Hospital
Houston, TX
Tel: (713) 797-1616

UTAH

Intermountain Shriners Hospital
Salt Lake City, UT
Tel: (801) 536-3500

WASHINGTON

Spokane Shriners Hospital
Spokane, WA
Tel: (509) 455-7844

CANADA

Shriners Hospitals
1529 Cedar Avenue
Montreal, PQ H3G 1A6
CANADA

MEXICO

Shriners Hospitals
Suhil No. 152
Col El Rosario Delg.
Coayocan, 04380
MEXICO

IN EVERY ISSUE

EXCEPTIONAL PARENT'S "Search and Respond" column affords parents, caregivers, and professionals the opportunity to exchange information about their practical experiences in meeting the everyday challenges of life with a child or adolescent who has a disability. We try to print as many Search and Respond letters as possible in each issue and on our Web site: **www.eparent.com**. You can write, fax, or e-mail your letters to: EXCEPTIONAL PARENT magazine, 555 Kinderkamack Road, Oradell, NJ, 07649; fax: (201) 634-6570; e-mail: epedit@aol.com; or visit www.eparent.com on the Web and click on "Search and Respond" which is located on the homepage. It is important to indicate whether the letter being sent is a "Search" or a "Respond." When sending a "Respond," please indicate the title, initials, month, and year of the "Search" letter you are answering. All responses are also forwarded to the writers of the "Search" letters, and most are published. Due to spacing issues, all letters may be edited. (As with all matters concerning medical care and advice, individuals are also expected to consult the appropriate professionals regarding care.)

Developmental Disabilities Councils

Developmental Disability Councils, under the Developmental Disability Assistance and Bill of Rights Act (DDBRA) of 1994, are responsible for allocating funds for services and supports for people with developmental disabilities. There is one in each state and their function is to enable individuals to have the opportunity to make choices regarding their quality of life and to be included in the community. For more information on legislation and you or your child's rights under the DDBRA in your state, contact the federal government's **Administration on Developmental Disabilities Administration for Children and Families U.S. Dept. of Health and Human Services**, Mail Stop: HHH 300-F, 370 L'Enfant Promenade, SW, Washington, D.C. 20447; Tel: (202) 690-6590; Web site: http://www.acf.dhhs.gov; E-mail: add@acf.dhhs.gov. Below is a state-wide list.When available, World Wide Web sites and e-mail addresses have been included. Web sites are listed with the standard **http://** before each. E-mail addresses are indicated by the symbol, ✉. (Unless otherwise indicated, all telephone numbers are for voice only.)

NADDC-National Association of Developmental Disabilities Councils
1234 Massachusetts Ave, NW, Ste. 103, Washington, DC 20005
(202) 347-1234
(202) 347-4023 (fax)
http://www.naddc.org;
✉rprice@naddc.org.

The Alabama Council for Developmental Disabilities
100 North Union St.
PO Box 301410
Montgomery, AL 36130-1410
(334) 242-3973; (800) 232-2158
(334) 242-0797 (fax):
http://www.asc.edu

Alaska Div. of Mental Health and Developmental Disabilities.
350 Main St., Rm. 214
PO Box 110620
Juneau, AK 99811-0620
(907) 465-3370 (907) 465-2225 (TTY)
(907) 465-2668 (fax)
http://www.hss.state.ak.us

Arkansas Dept. of Developmental Disabilities
Freeway Medical Tower
5800 West 10th, Ste. 805
Little Rock, AR 72204
(501) 661-2736
(501) 661-2736 (TDD)
501-661-2399 (fax)
✉wstewart@mail.doh.state.ar.us

Arizona Div. of Developmental Disabilities
1789 West Jefferson St.,
PO Box 6123-791A
Phoenix, AZ 85005-6123
(602) 542-0419; (602) 542-6870 (fax)

California State Council on Developmental Disabilities
2000 O St., Ste 100
Sacramento,CA 95814
(916) 322-8481; (916) 324-8420 (TDD)
(916) 443-4957 (fax)
http://www.scdd.ca.gov
✉scdd@dss.ca.gov

Colorado Developmental Disabilities Services
3824 W. Princeton Circle
Denver, CO 80236
(303) 866-7450; (303) 866-7470 (fax)
http://www.cdhs.state.co.us/

Connecticut Dept. on Mental Retardation Birth to Three
460 Capitol Ave.
Hartford, CT 06106
(860) 418-6147; (860) 418-6003 (fax)
http://www.state.ct.us//dmr/;
✉dmrct.co@po.state.ct.us

District of Columbia, Human Services Dept.
801 N. Capitol St.
Washington DC 21002
(202) 279-6000
http://www.washington.dc.us/agencylist

Delaware Consortium of Developmental Disabilities Council
2102 Weatherton Dr.
Wilmington, DE 19810
(302) 529-7270; (302) 529-7271 (fax)
http://www.cddc.com

Florida Developmental Disabilities Council
124 Marriott Dr., Ste. 203
Tallahassee, Florida 32301-2981.
(904) 488-4180; (800) 580-7801
(904) 488-0956 (TTY)
(904) 922-6702 (fax)
✉fddc@nettally.com

Georgia Alliance on Developmental Disabilities (AADD)
828 West Peachtree Street, NW,
Ste. 304, Atlanta,GA 30308
(404) 881-9777 (voice/fax)
http://www.aadd.org

Indiana Institute on Disability and Community
2853 E. 10th St.
Bloomington, IN 47408
(812) 855-6508; (812) 855-9630 (fax)
(812) 855-9396 (TTY)
http://www.iddc.indiana.edu
✉foshaj@indiana.edu

Iowa Dept. of Developmental Disabilities
617 E. Second St.
Des Moines, IA 50309
(515) 281-9083; (515) 281-9087 (fax)
✉bharker@dhs.state.ia.us

Idaho Dept. of Health and Welfare
450 W. State St., 10th fl.
Boise, Idaho 83720-0036
(208) 334-5500; (308) 334-6558 (fax)
http://www.state.id.us/

Illinois Planning Council on Developmental Disabilities
830 S. Spring St.
Springfield, IL 62704
(217) 782-9696 (Voice/TTY)
(217) 524-5339 (fax)

Kansas Council on Developmental Disabilities
915 SW Harrison
Topeka, KS 66612
(785) 296-2608; (785) 296-2861 (fax)
http://www.ksc.geo.ukans.edu/kcdd.
✉rhys@midus.net

Kentucky Dept. of Developmental Disabilities
275 E. Main St.
Frankfurt, KY 40601
(900) 928-6583; (502) 564-3844 (fax)
✉rdglass@mhrdmc.chr.state.ky.us

Louisiana Developmental Disabilities Council
PO Box 3455
Baton Rouge, LA 70821-3455
(225) 342 6804; (225) 342-1970 (fax)

Maryland Developmental Disabilities Council
300 W. Lexington St, Box 10
Baltimore, MD 21201
(410) 333-3688; (410) 333-3686 (fax)

Massachusetts Developmental Disabilities Network
160 N. Washington St.
Boston, MA 02114
(617) 727-5608; (617) 624-7577 (fax)

Maine Dept. of Mental Health, Mental Retardation and Abuse Services Office of Medicaid and Managed Care
State House Station 165
Augusta, ME 04333
(207) 287-4230; (207) 287-7285 (TTY)
(207) 287-4107 (fax)
http://www.state.me.us

Mississippi Developmental Disabilities Council
1101 Robert E. Lee Building
Jackson, MS 39201
(601) 359-1270; (601) 359-6295 (fax)
(601) 359-6230 (TDD)

Missouri Developmental Disabilities Resource Center
1706 E. Elm St.
Jefferson City, MO 65102.
(573) 751-4054
http://www.modmh.state.mo.us

Minnesota Dept. of Human Services
444 Lafayette Rd N.
St. Paul, MN 55155-3857
(651) 297-4112; (651) 582-1962 (fax)
http://www.dhs.state.mn.us

Montana Dept. of Public Health and Human Services Developmental Disabilities
111 North Sanders
PO Box 4210-59604
Helena, MT 59620
(406) 444-2995; (406) 444-0230 (fax)
http://www.dphhs.state.mt.us

Nebraska Health and Human Services Developmental Disability System
PO Box 94728
Lincoln, NE 68508-4728
(402) 471-5110; (402) 471-5094 (fax)
http://www.hhs.state.ne.us

Nevada Dept. of Developmental Disabilities
711 S. Stewart St.
Carson City, NV 89710
(702) 687-4452
702) 687-3388 (TDD)
(702) 687-3292 (fax)
✉tkvogel@govmail.state.nv.us

New Hampshire Developmental Disabilities Council
The Concord Center,
10 Ferry St., Box 315
Concord, NH 03301-5081.
(603) 271-3236; (603) 271-1156 (fax)
✉http://www.state.nh.us/dhhs

New Jersey Dept. of Human Services
State Office on Disability Services
PO Box 700
Trenton, NJ 08625-0700
(609) 292-7800; (800) 285-3036
(609) 292-1210 (TTY)
(609) 292-1233 (fax)
http://www.state.nj.us/humanservices/offdis

New Mexico Dept. of Health and Human Services
1190 Saint Francis Dr.,
PO Box 26110
Santa Fe, NM 87502
(505) 827-2574; (505) 827-2455 (fax)
http://www.state.nm.us/state/agencies

New York State Office on Mental Retardation and Developmental Disabilities
44 Holland Ave.
Albany, NY 12229-0001
(518) 473-9689.

North Carolina Div. Mental Health-Developmental Disabilities and Substance Abuse Services
Albemarle Building, 3001 MSC
Raleigh, N.C. 27699-3001
(919) 733-7011; (919) 733-9455 (fax)
http://www.dhhs.state.nc.us

The North Dakota Developmental Disabilities Council
600 E. Boulevard Ave.
Bismarck, ND 58505-0250.
(701) 328-8953; (701) 328-8969 (fax)
✉sowalt@state.nd.us

Ohio Developmental Disabilities Council
8 E. Long St., 12th fl.
Columbus, OH 43215-0415
(614) 466-5205; (614) 466-0948 (fax)

Oklahoma Developmental Disabilities Services Division
PO Box 25352,
Oklahoma City, OK 73125
(405) 521-6267; (405) 522-3037(fax)
http://www.okdhs.org

Oregon Dept. of Human Resources Developmental Disabilities Services Office
2575 Bittern St. NE, PO Box 14250
Salem, OR 97309.
(503) 945-9774; (503) 373-7274 (fax)

Pennsylvania Developmental Disabilities Council
Forum Building, Room 561
Harrisburg, PA 17120-0025
(717) 787-6057; (717) 772-0738 (fax)
✉tmulholland@dpw.state.pa.us.

Rhode Island Developmental Disabilities Council
14 Harrington Rd.
Cranston, RI 02920
(401) 462-3191 (voice/TDD)
(401) 462-3570 (fax)
http://www.riddc.org
✉riddc@riddc.org

South Carolina Dept. of Disabilities and Special Needs
PO Box 4706
Columbia, SC 29240
(803) 898-9600 (voice/TTY)
(888) 376-4636
(803) 898-9653 (fax)
http://www.state.sc.us/ddsn
✉ddsnweb@ddsn.state.sc.us

South Dakota Council on Developmental Disabilities
Hillsview Plaza, E Highway 34
c/o 500 East Capitol
Pierre, SD 57501-5070
(605) 773-6369; (605) 773-5483 (fax)
http://www.state.sd.us/dhs/ddc

Tennessee Boling Center for Developmental Disabilities
711 Jefferson
Memphis, TN 38105
(901) 448-6511; (888) 572-2249;
(901) 448-4677 (TTY)
(901) 448-7097 (fax)

Texas Dept. of Mental Health and Mental Retardation
PO Box 12668
Austin, TX 78711-2668
(512) 454-3761; (512) 206-4894 (fax)

Utah Dept. of Developmental Disabilities
555 East 300 South, Ste. 201
Salt Lake City, UT 84102
(801) 533-4128 (voice and TDD)
(801) 533-5305 (fax)
http://www.gcpd.state.ut.us
cchamble@state.ut.us

Vermont Dept. of Developmental and Mental Health Services
103 S. Main St., Weeks Bldg.
Waterbury, VT 05671-1601.
(802) 241-2650; (802) 241-3052 (fax)
✉cbiff@ddmhs.state.vt.us.

Washington State Division of Developmental Disabilities
PO Box 45310
Olympia, WA 98504-5310
(360) 902-8444
(800) 833-6384 (voice/relay)
(360) 902-8455 (TTY)
(360) 902-8482 (fax)

West Virginia Developmental Disabilities Planning Council
110 Stockton St.
Charleston, WV 25312
(304) 558-0416 (304) 558-0941 (fax)
http://www.wvdrs.wvnet.edu/
✉stewaj@wvnvm.wvnet.edu

Wisconsin Developmental Disabilities Council
722 Williamson St., PO Box 7851
Madison, WI 53707-7851
(608) 267-7826; (608) 267-3906 (fax)
✉wiswcdd@dhfs.state.wi.us

Wyoming Division of Developmental Disabilities
122 W 25th St.
Herschler Building,1st floor
West Cheyenne, WY 82002.
(307) 777-7115; (307) 777-6047 (fax)

The Puerto Rico Developmental Disabilities Council
Ponce de Leon Ave.,
#1225, Box 9541-1225
First Floor Office (Lobby)
Santurce, Puerto Rico 00908
(787) 722-0595
(787) 721-3622.(fax)

Title V Program Contacts

Every state has a Title V Program which is funded, in part, through the Federal Title V Block Grant that provides health-related services to children with special healthcare needs—sometimes abbreviated as "CSHCN"—and their families. Title V Programs also provide assistance in accessing other services that CSHCN and their families need, such as parent support and information networks. The financial eligibility criteria, residency criteria, and medical eligibility criteria for these Programs varies from state to state. These Programs are also known by different names in different states. The following is a list of contacts in each of the state Title V CSHCN Programs. The listing is based on the *Directory of State Title V CSHCN Programs: Eligibility and Scope of Services*. This report was developed by the Institute for Child Health Policy in Gainesville, FL, with financial support from the Maternal and Child Health Bureau, (US Department of Health and Human Services) and with technical assistance from the Association of Maternal and Child Health Programs. The information contained in this report is also available through the Internet. The address on the World Wide Web is **http://www.ichp.edu.**

USING THIS DIRECTORY
When available, World Wide Web sites and e-mail addresses have been included. Web sites are listed with the standard **http://** before each. E-mail addresses are indicated by the symbol, ✉. (Unless otherwise indicated, all telephone numbers are for voice only.)

ALABAMA

Children's Rehabilitation Service (CRS)
2129 E. South Blvd.
PO Box 11586
Montgomery, AL 36111-0586
(800) 846-3697 (in state)
(334) 281-8780 ext. 281
(334) 281-1973 (fax)
✉ckendall@rehab.state.al.us
http://www.rehab.state.al.us/children.html

ALASKA

Health Care Program for Children with Special Needs (HCP-CSN)
Section of Family Health
Special Needs Services Unit
1231 Gambell St.
Anchorage, AK 99501-4627
(800) 478-2221
(907) 269-3460
(907) 269-3465 (fax)
✉jbrown@health.state.ak.us
✉kamartin@health.state.ak.us

ARIZONA

Office of Children with Special Health Care Needs (CSHCN)
Department of Health Services
1740 West Adams Street, Room 200
Phoenix, AZ 85007
(800) 232-1676
(602) 542-1860
(602) 542-2589 (fax)
✉sburke@hs.state.az.us

ARKANSAS

Children's Medical Services (CMS)
PO Box 1437, Slot 526
Little Rock, AR 72203-1437
(800) 482-5850 Ext. 22277 (in state only)
(501) 682-2277
(501) 682-8224
(501) 682-8247 (fax)
✉Nancy.Church@Medical.State.AR.US

CALIFORNIA

California Children Services (CCS)
714 P. Street, #350
Sacramento, CA 95814-7320
(916) 654-0832
(916) 653-8271 (fax)
✉Mgregory@dhs.ca.gov

COLORADO

Health Care Program for Children with Special Needs (HCD)
FCHSD-HCP-A4
4300 Cherrycreek Dr. S.
Denver, CO 80246-1530
(800) 688-7777
(303) 692-2370
(303) 782-5576 (fax)
✉SANDRA.JACQUEZ@STATE.CO.US

CONNECTICUT

Children with Special Needs (CSHCN) Program
State of Connecticut
Department. of Public Health
410 Capitol Ave., MS #11-MAT
PO Box 340308
Hartford, CT 06134-0308
(800) 505-2000
(860) 509-8074
(860) 509-7720 (fax)
✉davi166w@cdc.gov

DELAWARE

Children with Special Health Care Needs
Delaware Health and Social Services
Division of Public Health
Jesse Cooper Bldg
PO Box 637
Dover, DE 19903
(302) 739-4785
(302) 739-6653 (fax)
✉1weeks-news@state.de.us

DISTRICT OF COLUMBIA

Health Services for Children with Special Needs
District of Columbia General Hospital
Building 10
19th St and Massachusetts Ave., SE
Washington, DC 20003
(202) 675-7148
(202) 675-7694 (fax)

FLORIDA

Children's Medical Services (CMS)
Department of Health
1309 Winewood Blvd, Building 6, Room 130
Tallahassee, FL 32399-0700
mailing address:
Children's Mental Services
Department of Health
2020 Capital Circle SE, BIN #A06
Tallahassee, FL 32399-1707
(850) 487-2690
(850) 488-3813 (fax)
✉ERIC_G_HANDLER@DOH.STATE.FL.US
http://www.doh.state.fl.us

GEORGIA

Children's Mental Services
GA Department. of Human Resources
2600 Skyland Dr., NE
Lower Level
Atlanta, GA 30319-3640
(404) 659-0547
(404) 659-0537 (fax)
✉lls@dhr.state.ga.us.
http://www.ph.dhr.state.ga.us/

HAWAII

Children with Special Health Needs Branch
Hawaii State Department. of Health
741 Sunset Ave.
Honolulu, HI 96816
(800) 235-5477
(808) 955-7273
(808) 733-9070
(808) 733-9068 (fax)
✉plheu@mail.fhsd.health.state.hi.us

IDAHO

Children's Special Health Program (CSHP)
Idaho Department of Health and Welfare
450 W State St., 4th Fl.
PO Box 83720
Boise, ID 83720-0036
(800) 926-2588
(208) 334-5962
(208) 334-6581 (fax)
✉harrellb@idhw.state.id.us
http://www2.state.id.us/idahochild

ILLINOIS

University of Illinois at Chicago Division of Specialized Care for Children (DSCC)
2815 W. Washington, Ste. 300
PO Box 19481
Springfield, IL 62794-9481
(800) 332-3722
(800) 332-DSCC
(217) 793-2340
(217) 793-0773 (fax)
✉cnonufer@uic.edu
http://www.uic.edu/hsc/dscc

INDIANA

Children's Special Health Care Services (CSHCS)
Indiana State Department. of Health
2 N. Meridian St., Section 7-B
Indianapolis, IN 46204
(800) 475-1355
(317) 233-5578
(317) 233-5609 (fax)
✉wgettelf@isdh.state.in.us

IOWA

Child Health Specialty Clinics (CHSC)
University Hospital School
100 Hawkins Dr., Room. 254
Iowa City, IA 52242-1011
(800) 779-2001
(319) 356-1456
(319) 356-3715 (fax)
✉Andrew-Penziner@UIOWA.EDU

KANSAS

Services for Children with Special Health Care Needs
Landon State Office Bldg.
900 SW. Jackson 1005 N
Topeka, KS 66612-1220
(800) 332-6262
(785) 296-1316
(785) 296-8616 (fax)
www.kdhe.state.ks.us/shs
✉JKendall@KDHE.State.KS.US
http://www.kdhe.state.ks.us/SHS/

KENTUCKY

Commission for Children with Special Health Care Needs
982 Eastern Parkway
Louisville, KY 40217
(800) 232-1160 (in state only)
(502) 595-4459
(502) 595-4673 (fax)
✉ann.marks@mail.state.ky.us
http://cfc-chs.chr.state.ky.uschs/cwshcn/index.htm

LOUISIANA

Children's Special Health Services
PO Box 60630
Room. 607
New Orleans, LA 70160
(800) 922-3425
(800) 256-1633
(504) 568-5055
(504) 568-7529 (fax)
✉lrose@dhhmail.dhh.state.la.us

MAINE

Coordinated Care Services for Children with Special Health Needs
Department of Health
Division of Community and Family Health
151 Capitol St.
11 State House Station
Augusta, ME 04333-0011
(800) 698-3624
(800) 287-8015
(207) 287-5350
(207) 287-5355 (fax)
✉toni.g.wall@state.me.us

MARYLAND

Children's Medical Services
Maryland State Department of Health and Mental Hygiene
201 W. Preston St.
Baltimore, MD 21201
(800) 456-8900
(800) 638-8864
(410) 767-6749
(410) 333-7956 (fax)
✉MALONES@DHMH.STATE.MD.US
MDPUBLICHEALTH.ORG

MASSACHUSETTS

Family and Community Support Division for Special Health Needs
Bureau of Family and Community Health
Department of Public Health
250 Washington St., 4th Fl.
Boston, MA 02108-4619
(800) 882-1435
(617) 624-5970
(617) 624-5990 (fax)
✉rosalie.edes@state.ma.us

MICHIGAN

Michigan Department of Community Health
Children's Special Health Care Services Plan Division
400 S. Pine
Lansing, MI 48933
(800) 359-3722
(800) 788-7889
(517) 241-8207
(517) 241-8970 (fax)
✉finnj@state.mi.us

MINNESOTA

Minnesota Children with Special Health Needs (MCSHN)
Minnesota Department of Health
Division of Family Health
85 E. 7th Place, Ste 400
St. Paul, MN 55101
(800) 728-5420
(651) 281-9965
(651) 215-8953 (fax)

MISSISSIPPI

Children with Special Health Care Needs
Mississippi State Department of Health
421 Stadium Circle
PO Box 1700
Jackson, MS 39215-1700
(800) 844-0898
(601) 987-3965
(601) 987-5560 (fax)

MISSOURI

Children with Special Health Care Needs
Missouri Department of Health
PO Box 570
Jefferson City, MO 65102-0570
(800) 451-0669
(314) 751-6246
(573) 751-6237 (fax)
✉brownr@mail.health.state.mo.us

Title V Program Contacts

MONTANA

Special Health Services
Department of Public Health and Human Services
Cogswell Building, Room C314
Helena, MT 59620
(800) 762-9891 (in state for parents only)
(406) 444-3622
(406) 444-2606 (fax)
✉shwagner@mt.gov
http://www.dphhs.state.mt.us/hpsd/

NEBRASKA

Nebraska Department of Health and Human Services
Nebraska Department. of Health and Human Services
PO Box 95044
Lincoln, NE 68509-5044
(800) 358-8802
(800) 862-1889
(402) 471-9328
(402) 471-6352 (fax)
✉RSNUTTJ@hhs.state.ne.us
http://www.HHS.state.ne.us/chd/chdindex.htm

NEVADA

Nevada State Health Division
Bureau of Family Health Services
505 East King St.., Room 200
Carson City, NV 89710
(800) 992-0900 Ext. 44285
(702) 684-4285
(702) 684-4245 (fax)
✉jwright@govmail.state.nv.us

NEW HAMPSHIRE

Bureau of Special Medical Services
Office of Health Management
6 Hazen Dr.
Concord, NH 03301-6527
(800) 852-3345 Ext. 4488 (in state)
(603) 271-4488
(603) 271-4902 (fax)

NEW JERSEY

Special Child, Adult and Early Intervention Services (SCAEIS)
Department of Health and Senior Services
PO Box 364
Trenton, NJ 08625-0364
(800) 328-3838
(609) 984-0755
(609) 292-3580 (fax)
✉mg5@doh.state.nj.us
http://www.state.nj.us/health/fhs

NEW MEXICO

Children's Medical Services
New Mexico Department of Health
Public Health Division
1190 St. Francis Drive
Santa Fe, NM 87505
(800) 552-8195
(505) 827-2548
(505) 827-1697 (fax)
✉Marilyns@DOH.STATE.NM.US

NEW YORK

Physically Handicapped Children's Program
New York State Department of Health
Bureau of Child and Adolescent Health
Empire State Plaza
Rm. 208, Corning Tower
Albany, NY 12237-0618
(800) 522-5006 (bilinqual)
(518) 474-2001
(518) 473-8673 (fax)

NORTH CAROLINA

Children's Special Health Services
Department. of Health and Human Services
Division of Public Health
1330 St. Mary's Street
PO Box 29597
Raleigh, NC 27626-0597
(800) 737-3028
(919) 715-3808
(919) 733-0292
919) 715-3187 (fax)
✉tom.vitaglione@ncmail.net
http://llwch.dhhs.state.nc.us

NORTH DAKOTA

Children's Special Health Services
Department of Human Services
State Capitol - Judicial Wing
600 E. Boulevard Ave. Department. 325
Bismarck, ND 58505-0269
(800) 755-2714
(800) 472-2286
(701) 328-2436
(701) 328-2359 (fax)
✉SOGALT@.STATE.ND.US
http://www.state.nd.us/

OHIO

Department of Health
Bureau for Children with Medical Handicaps
PO Box 1603
Columbus, OH 43216-1603
(800) 755-GROW (for parents only)
(614) 466-1549
(614) 728-3616 (fax)
✉jbryant@gw.odh.state.us
http://www.odh.state.oh.us/

OKLAHOMA

Chilodren with Special Health Care Needs
Department of Human Services
Family Support Services Division
PO Box 25352
Oklahoma City, OK 73125
(800) 426-2747
(405) 521-3076
(405) 521-4158 (fax)
http://www.okdhs.org

OREGON

Oregon Services for Children with Special Health Care Needs
Oregon Health Sciences University
707 SW. Gaines
Portland, OR 97201
(800) 723-3638
(503) 494-8369
(503) 494-6868 (fax)
http://www.ohsu.edu

PENNSYLVANIA

Pennsylvania Department of Health
Division of Special Health Care Programs
PO Box 90, Room 724
Harrisburg, PA 17108
(800) 852-4453
(800) 986-4550
(717) 783-5436
(717) 772-0323 (fax)
✉gstock@health.state.pa.us

RHODE ISLAND

Crippled Children's Services
Division of Family Health
3 Capitol Hill
Providence, RI 02908
(800) 942-7434
(401) 222-2312
(401) 222-1442 (fax)

SOUTH CAROLINA

Children's Rehabilitative Services
South Carolina Department of Health and Environment Control
Mills - Jarrett Complex
Box 101106
Columbia, SC 29211
(800) 868-0404
(803) 898-0784
(803) 898-0613 (fax)
http://www.state.sc.us/dhec/hsshc.htm
http://www.state.sc.us/dhec/bumtgin.htm

SOUTH DAKOTA

Children's Special Health Services
South Dakota Department of Health
Children's Special Health Services
615 E 4th St.
Pierre, SD 57501
(800) 529-5000
(605) 773-3737
(605) 773-5942 (fax)
✉Nancy.Hoyme@state.sd.us
http://www.state.sd.us/doh

TENNESSEE

Children's Special Services
Tennessee Department of Health
Cordell Hull Building 5th Floor
425 5th Ave., North
Nashville, TN 37247-4850
(615) 741-0310 or -8530
(615) 741-1063 (fax)
✉jcundall@mail.state.tn.us

TEXAS

Chronically Ill and Disabled Children's Services Program (CIDC)
Texas Department. of Health
1100 West 49th St.
Austin, TX 78756-3179
(800) 252-8023
(512) 458-7355
(512) 458-7238 (fax)
✉susan.penfield@tdh.state.tx.us

UTAH

Children with Special Health Care Needs
Utah Department of Health
Community and Family Health Services Division
44 N. Medical Drive
PO Box 144610
Salt Lake City, UT 84114-4610
(800) 829-8200
(801) 584-8239
(801) 584-8488 (fax)
✉ftait@doh.state.ut.us
http://hlunix.hl.state.ut.us/cfhs/cshcn

VERMONT

Vermont Department Health (CSHN)
Division for Children with Special Health Needs
108 Cherry St.
PO Box 70
Burlington, VT 05402
(800) 660-4427 (in state)
(802) 863-7338
(802) 863-7635 (fax)
✉CHASSLE@VDH.STATE.VT.US
✉SBROOKS@VDH.STATE.VT.US

VIRGINIA

Department of Health
Children with Special Health Care Needs Program
Division of Child and Adolescent Health, Rm. 138
PO Box 2448
Richmond, VA 23218
(800) 523-4019
(804) 786-3693
(804) 225-3307 (fax)
✉nbullock@vdh.state.va.us
http://www.vdh.state.va.us/fhs/child/specialneeds.htm

WASHINGTON

Department of Health
Community and Family Health
Children with Special Health Care Needs Program
PO Box 47880
Olympia, WA 98504-7880
(800) 322-2588
(360) 236-3521
(360) 586-7868 (fax)
✉mjf0303@doh.wa.gov

WEST VIRGINIA

Office of Maternal and Child Health
Bureau for Public Health
1411 Virginia St., E.
Charleston, WV 25301
(800) 642-9704
(800) 642-8522
(304) 558-5388
(304) 558-2183 (fax,
✉kaypropst@wvdhhr.org
✉patmoss@wvdhhr.org

WISCONSIN

Department of Health and Family Services
Division of Public Health
Bureau of Family and Community Health
Family Health Section
CSHCN Unit
1414 E. Washington Ave., Rm. 167
Madison, WI 53703-3044
(800) 441-4576
(608) 266-5485
(608) 267-3561
(608) 267-3824 (fax)
✉kuttecsm@dhfs,state,wi.us
✉fleissa@dhfs.state.wi.us

WYOMING

Children's Health Services
Department of Health
Division of Public Health
4th Fl. Hathaway Bldg
Cheyenne, WY 82002
(800) 438-5797
(307) 777-7941
(307) 777-5402 (fax)
✉DAILES@MISSC.STATE.WY.US

Thanks to the Courage, Determination and Pioneering Spirit of Patients and their Families

Vagus Nerve Stimulation (VNS™)

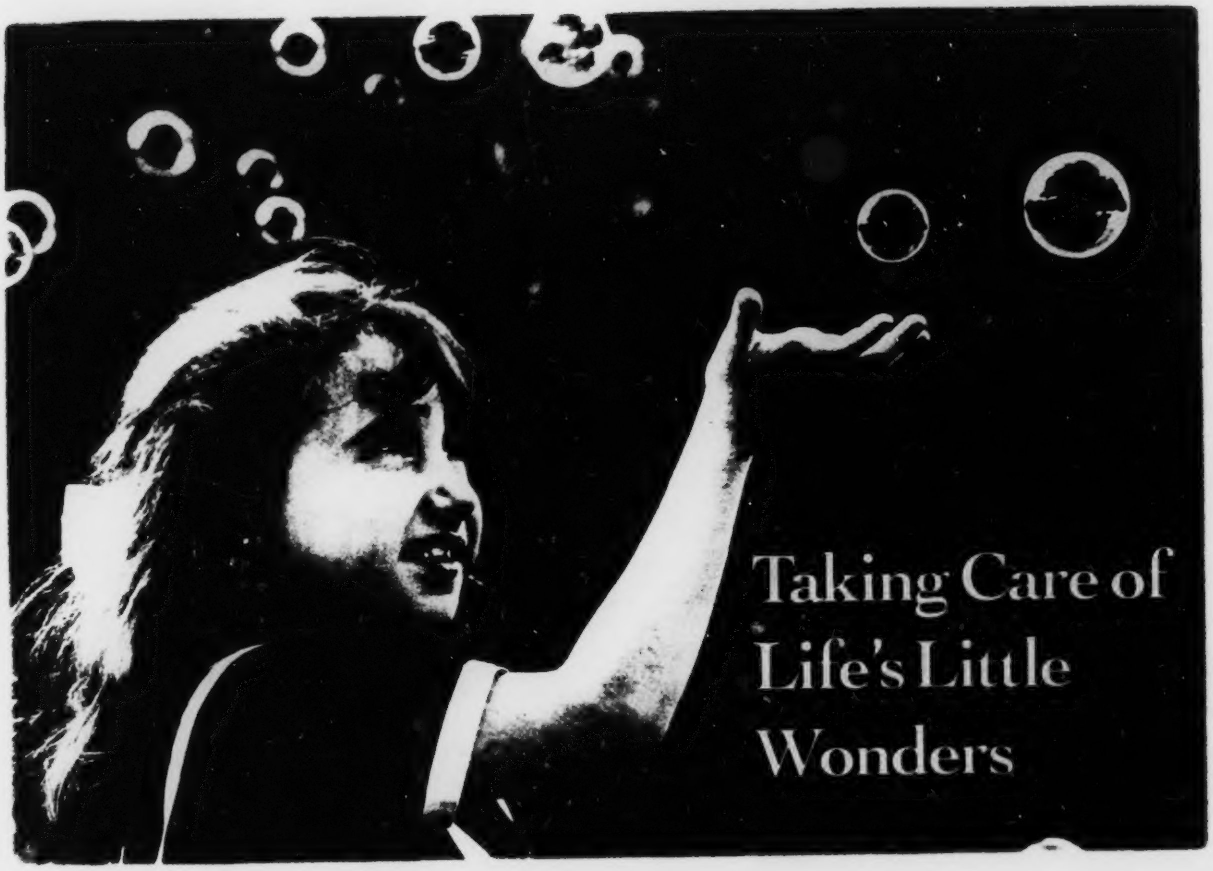
is the first new FDA approved non-pharmacological treatment for partial seizures in 100 years.

On July 16, 1997, VNS was approved by the FDA "for use as an adjunctive therapy in reducing the frequency of seizures in adults and adolescents over 12 years of age with partial onset seizures which are refractory to antiepileptic medications." Since then, over 4,000 patients and their families have shared in the Cyberonics Oppportunity.

For more information on VNS:
888-VNS-STIM
www.cyberonics.com

Cyberonics
DEVICES FOR EPILEPSY

Circle #42



At Children's Hospital, we know what it takes to work wonders in the care of a child. For 80 years, we've provided pediatric care with a philosophy that has remained unchanged – we believe in not only improving the health of our patients, but in enhancing the quality of their lives. As one of the Southeast's largest providers of specialized pediatric services, we take an interdisciplinary approach to treatment, delivering family-centered care through a variety of programs:

- Our **Pediatric Rehabilitation Program** offers inpatient and outpatient services at several locations with customized treatment plans to help each child reach full functional potential.

- Opened in 1999, our **Transitional Care Unit** provides subacute care with active participation of families and goal of transition to home.

- Our **Pediatric Orthopaedic Program** provides services ranging from inpatient surgery to outpatient care – always incorporating the unique needs of each child.

- Our **Assistive Technology Program** offers evaluation and training on the newest augmentative communication devices and daily living aids.

- We have **32 Specialty Clinics** for children with chronic conditions as well as innovative programs like our **Pediatric Feeding Disorders Program** and the **Neurosciences Center for Children.**

At Children's Hospital we understand that quality health care takes more than expertise. It takes vision. And compassion. With this in mind, we are continually expanding our resources to provide for the special needs of all children. Because *every* child is a wonderful gift.

Children's Hospital

Specialty Services for Children

Child Development • Neurosciences • Orthopaedics • Rehabilitation

2924 Brook Road • Richmond, Virginia 23220-1298
Information & Referrals: (804) 228-5818
TDD via Virginia Relay Center 1-800-828-1120
www.childrenshosp-richmond.org
Circle #34

Children's Extended Care Center

Where little things make all the difference

Staff members who are experts in developmental disabilities

A nationally recognized program that integrates residents into the community

Up-to-date assistive technologies that create new opportunities

Access to specialists at Children's Hospital in Boston

For more information, please contact:

Director of Social Services
Children's Extended Care Center
22 Hillside Avenue
Groton, MA 01450
(978) 448-3388
FAX (978) 448-9695
TTY (978) 448-5541

A subsidiary of
Children's Medical Center

These are descriptions of Children's Extended Care Center (CECC), which provides comprehensive health care, therapy and education in a residential setting for children with complex medical and developmental needs.

But it's the little things that make all the difference.

"The staff show such devotion to the kids," says a parent whose 11-year-old son is a resident at CECC. "I don't know how they do it. Even little things never get overlooked, like keeping chapstick on hand for Matt's lips."

All staff members at CECC—from nurses to teachers to administrators to groundskeepers—extend extraordinary care to children everyday, in countless small ways. They know who enjoys hustle and bustle, who prefers peace and quiet. They remember to open a window to let in a spring breeze, or to choose flowers both for appearance and fragrance. Every wheelchair has a handwritten card on the back, alerting staff to that resident's likes and dislikes.

Located in Groton, Mass., CECC admits and offers short-term and long-term care to children from birth to age 22. All services are tailored to the needs of each child and family. In addition to receiving skilled nursing care, children participate in a school program, where an integrated curriculum matches activities with abilities.

Through the "Into the Community" program, CECC residents mix with the neighboring community and members of the community join activities at CECC. Several CECC residents attend nearby public schools for a few hours a week accompanied by a CECC staff member.

A subsidiary of Children's Medical Center, CECC is housed in a cheerful, two-story building in a residential neighborhood. The grounds include a large outdoor play area, gardens, and a swimming pool, allowing residents and visitors to enjoy a variety of outdoor activities.

Circle #33

Guide to Theme &

Amusement parks are synonymous with family fun and excitement. In order to ensure that visiting one of these parks is a pleasant experience for their child with a disability, parents need to know the accessibility features of the park before planning a trip. Below, we have provided a state-by-state listing of amusement and theme parks that participated in our accessibility survey. Any special services are listed at the bottom of each entry and a Key to Services is provided on every other page to help you find the park that will let your child have the most fun with the least difficulty.

ALABAMA

Southern Adventures
2150 Leeman Ferry Circle
Huntsville, AL 35801-5324
(205) 880-6599
1,2,3,4,6,11,13

VisionLand
5051 Prince Street
Bessemer, AL 35022
(205) 581-4750
1,2,3,4,5,6,7,11,12,13,14

ARIZONA

Castles N' Coasters
9445 North Metro Parkway East
Phoenix, AZ 85051
(602) 997-7575
1,2,3,7,13,15; most rides have stairs built during the 1920's

Golfland/Sunsplash Water Park
155 West Hampton Ave
Mesa, AZ 85210
(602) 834-8319
1,2,3,4,6,11,13,14,15

Old Tucson Studios
201 South Kinney Road
Tucson, AZ 85735
(520) 883-0100
1,2,3,4,5,6,7,9,11,13,14; allows free admission for some special needs groups to get their feedback on the park's accessibility and how it can be improved; have dirt streets and some wooden sidewalks; on-staff EMT.

CALIFORNIA

Rawhide
23023 North Scottsdale Road
Scottsdale, AZ 85255
(602) 502-5600
1,2,3,4,5,6,7,9,11,13,14

Disneyland
1313 Harbor Blvd, PO Box 3232
Anahiem, CA 92803-3232
(714) 781-4560
1,2,3,4,5,6,7,8,9,11,13,14; accessible transportation from hotels to the park, written scripts of all shows available, reflective and video captioning available

Escondido Family Fun Center
830 Dan Way
Escondido, CA 92025
(760) 742-3045
1,3,4,6,11,14; can assign someone to a visitor if help is needed; bendable golfclubs available for those playing miniature golf in a wheelchair; first aid equipment available.

Funderland
PO Box 221532
Sacramento, CA 95822-8532
(916) 456-0131
1,6,11,13

Knott's Berry Farm
8039 Beach Blvd
Buena Park, CA 90620
(714) 220-5200
1,2,3,4,5,6,7,8,9,11,12,13,14,15,16; Opened year round except for Christmas Day; guest services trained to help visitors with disabilities

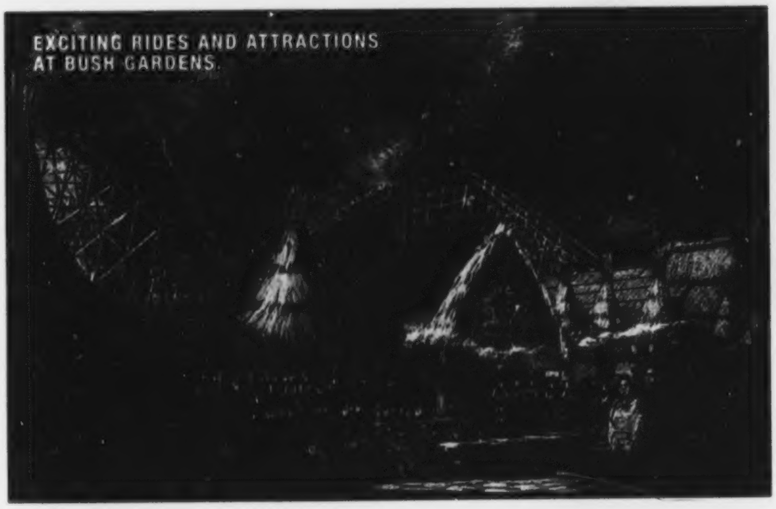
The New Marine World Theme Park
Marine World Parkway
Vallejo, CA 94589
(707) 644-4000
1,2,3,4,5,6,7,8,11,13,14,15; Deaf Awareness Day every year in the late summer

Outrageous Waters Water Park and Fun Center
6845 Old Highway 55
Clearlake, CA 95422
(707) 995-1402
1,2,3,5,7,13,15; only one ride is accessible, "Lazy River" is accessible

Paramount Great America
Great American Parkway S.
santa Clara, CA 95052-1776
(408) 988-1776
1,2,3,4,5,6,7,8,11,12,13,14,15

Raging Waters
11 Raging Waters Drive
San Dimas, CA 91773-3928
(909) 592-8181
1,2,3,4,6,10,11,13,15

Raging Waters
Corner of Capitol and Telly Road
San Jose, CA 95151-1368
(408) 238-9900
1,2,3,4,6,8,11,12,13,15



EXCITING RIDES AND ATTRACTIONS AT BUSH GARDENS.

San Diego Coaster Company
3190 Mission Blvd
San Diego, CA 92109
(619) 488-1549
1,3,4,6,10,11; Lifeguard stations

Santa Cruz Beach Boardwalk
400 Beach Street
Santa Cruz, CA 95060-5416
(408) 423-5590
1,2,3,4,6,11,13,14

Sea World of California
1720 South Shores Road
San Diego, CA 92109
(619) 222-6363
1,3,4,5,6,7,8,10,11,12,13,14,15

Universal Studios Hollywood
100 Universal City Plaza, SC31
Universal City, CA 91608-1085
(818) 777-1000
1,2,3,4,5,6,7,12,13

Wild Rivers Waterpark
8770 Irvine Center Drive
Irvine, CA 92718
(949) 786-Wild (9453)
1,2,3,5,7,12,15,16,17; many rides have stairs

Windsor Waterworks and Slide
8225 Condo Lane
Windsor, CA 95492
(707) 838-7360
1,2,3,4,6,11,13; will carry riders up-stairs; emt on staff

COLORADO

Elitch Gardens
299 Walnut
Denver, CO 80204
(303) 595-4fun (4386)
1,2,3,4,5,6,7,10,11,12,13,15

Royal Gorge Town and Railway
County Road 3A, off of Highway 50
Canon City, CO 81215-0008
(719) 275-5485
1,2,3,4,6,11,13,15

Santa's Workshop
North Pole, CO 80809
(719) 684-9432
1,2,3,4,6,11,12,13,14,15

Water World
1800 West 89th Ave
Denver, CO 80221
(303) 428-7488
1,2,3,4,6,10,11,13,14

CONNECTICUT

Quassy Amusement Park
Route 64
Middlebury, CT 06762
(203) 758-2913
1,2,3,4,6,11,13,14

DELAWARE

Funland
6 Delaware Ave
Rehoboth Beach, DE 19971
(302) 227-2785
1,2,3,5,13,15,16; City parking only

FLORIDA

Adventure Island
3605 Bougainvillea Ave
Tampa, FL 33612
(813) 987-5600
1,2,3,4,6,7,10,11,13; personal care service available upon request; call throughout the season for special ticket offers

Adventure Landing
1944 Beach Blvd.
Jacksonville Beach, FL 32250
(904) 246-4386
1,2,3,7,13,15

Florida Cypress Gardens
2641 South Lake Summit Drive
Cypress Gardens, FL 33884-0001
(941) 324-2111
1,2,4,5,6,7,11,12,13,15, advance notice needed to make sign language interpreters available.

Amusement Parks

Florida's Silver Springs
PO Box 370
Silver Springs, FL 34489-0370
(800) 274-7458
(850) 236-2121
1,2,3,4,5,6,7,8,11,13,14,15; language interpreters available on request.

Fun N' Wheels
3711 West Vine Street
Kissimmee, FL 34741
(407) 870-2222
1,3,6,11,13

Miami MetroZoo
12400 South W. 152nd Street
Miami, FL 33177
(305)251-0403
1,2,3,4,5,6,7,9,10,11,13; park rangers can help visitors around the park.

Miami Seaquarium
4400 Rickenbacker Causeway
Miami, FL 33149
(305) 361-5705
1,2,3,4,5,6,7,15; one venue not accessible reason for discount

Miracle Strip/Shipwreck Island
PO Box 2000
Panama City, FL 32402-2000
(850) 234-0386
1,2,3,4,5,6,11,13,14,15; have staff members that will assist getting in and out of rides.

Old Town
5770 West Irlo Bronson Highway
Kissimmee, FL 34746
(407) 396-4888
1,2,3,4,6,11

Santa's Magical Village Theme Park
4747 Hollywood Blvd
Hollywood, FL 33021
(954) 475-8505
1,2,3,4,6,10,11,13,14; open only from November to beginning of January

Walt Disney Attractions, Inc
PO Box 10500
Lake Buena Vista, FL 32830
(800) 4disney
1,2,3,4,5,6,7,8,9,11,12,13,14; written scripts available for all shows, reflective video captioning

Water Mania
6073 West Irlo Bronson Highway
Kissimme, FL 34747
(800) 527-3092
(407) 396-2626
1,2,3,4,6,10,11,13,15

THRILLS FOR THE WHOLE FAMILY!
DISNEY THEME PARKS.

GEORGIA

Lake Winnepesaukah Fun Town
PO Box 490
Rockville, GA 30741-0490
(706) 866-5681
1,2,3,4,5,6,11,14

Six Flags Over Georgia
PO Box 490
Atlanta, GA 30378
(770) 739-3400
1,2,3,4,5,6,7,8,11,12,13,14,15,16; "Deaf Day"

Wild Adventures
3766 Clayttville Road
Valdosta, GA 31601
(800) 808-0872
1,2,3,4,5,6,7,10,13

IDAHO

Silverwood Theme Park
North 2625 Highway 95
Atho, ID 83801
(208) 683-3400
1,3,4,6,7,12,13,14

Western Amusement Co.
PO Box 50276
Idaho Falls, ID 83405-0276
(208) 525-9814
1,2,3,4,6,7,11,13,14

ILLINOIS

Geauga Lake
1060 Aurora Rd
Auroa, IL 44202-8710
(330) 562-7131
1,2,3,4,5,6,7,11,12,13,14,15

Knight's Action Park
1700 Recreation Drive
Springfield, IL 62707
(217) 546-8881
1,2,3,5,7,10,13,15,16; pools with zero depth entry

Raging Rivers Waterpark
100 Palisades Parkway
Grafton, IL 62037
(618) 786-2345
1,2,3,4,6,8,11,12,13,14,15; EMT's and paramedics on staff know ASL; built on a hillside so no stairs needed for rides, lifeguards will assist visitors going up and down the hills, as well as carrying them into and out of pools.

Rockome Gardens
125 N. CR 425 E.
Arcola, IL 61910
(217) 268-4106
1,2,3,6,7,11,12,13,15

Six Flags Great America
Grand Ave, Exit 132
Gurnee, IL 60031
(847) 249-2133
1,2,3,4,5,6,7,11,12,13,14,15

INDIANA

Adventureland
Highway 13
North Webster, IN 46555
(219) 834-2554
1,2,3,5,7

Fun Spot
2365 North 200
West, Angola IN
46703-0704
(219) 833-2972
1,2,3,4,6,7,11,12,13,14

Holiday World and Splashin Safari
One Holiday Square
PO Box 179
Santa Claus, IN 47579-0179
(800) GO-SANTA
(467-2682)
fax: (812) 937-4401
http://www.holidayworld.com
1,2,3,4,5,6,7,11,12,13,14,15

Indiana Beach Amusement and Camp Resort
5224 East Indiana Beach Road
Monticello, IN 47960
(219) 583-4141
1,2,3,4,6,7,11,13

River Fair Family Fun Park
951 East Highway 131
Clarksville, IN 47129
(812) 284-3247
1,2,3,4,5,6,7,11,13,15; Limited # of accessible rides

IOWA

Adventureland
I-80 and Highway 65
Des Moines, IA 50316
(515) 266-2121
1,2,3,4,6,7,11,13,15; personal care attendants are available upon request

Arnolds Park
PO Box 609
Arnolds Park, IA 51331
(712) 332-7781
(800) 599-6995
1,2,3,4,6,7,11,13,14,15

KANSAS

Joyland
2801 South Hillside Drive
Wichita, KS 67216
(316) 684-0179
1,2,3,4,6,1,14

KENTUCKY

Guntown Mountian
PO Box 236
Cave City, KY 42127
(502) 773-3530
1,2,3,4,5,6,11,13,14

Key to Services

1. Accessible restrooms/ drinking fountains
2. Accessible telephones
3. Accessible restaurants
4. Accessible rides/attractions
5. Accessible theaters
6. Accessible parking
7. Wheelchair rentals (manual/electric)
8. Sign language interpreters
9. Braille/audio information guides
10. Personal care services/attendants
11. Guide dogs permitted
12. Guidebooks for visitors with disabilities
13. First aid station
14. Alternate entrances for rides
15. Special ticket rates
16. Assistive listening devices

Theme-Amusement Parks

Kentucky Action Park
3057 Mammouth Road
Cave City, KY 42127
(502) 773-2636
3,4,6,10,11,13,14

Six Flags Kentucky Kingdom and Hurricane Bay
937 Philips Lane
Louisville, KY 40209-0287
(502) 366-2331
1,2,3,5,6,7,8,13,14,15,16,17

MAINE

Palace Playland
One Old Orchard Street
Old Orchard Beach, ME 04064-0355
(207) 934-2001
1,4,6,11,13,14

York's Wild Kingdom Zoo and Amusement Park
Route One
York Beach, ME 03910
(800) 456-4911
1,3,5,7,13,15,16

MARYLAND

Adventure World Family Theme Park
13710 Central Ave
Largo, MD 20755-4210
(301) 249-1500
1,2,3,4,5,6,7,8,11,13,14,15

Frontier Town Western Theme Park
PO Box 691
Ocean City, MD 21842-0691
(410) 289-7877
1,3,6,11,13,14,15

Trimpers
PO Box 157
Ocean City, MD 21843-0691
(410) 289-8617
1,3,4,6,11,13,14

MASSACHUSETTS

FantasyLand
1300 Fall River Ave
Seekonk, MA 02771
(508) 226-6262
1 2,3,4,6,11,12,14,16

Riverside Park
1623 Main Street
Agawam, MA 01001-0307
(413) 786-9300
1,3,4,5,8,11,13,14,15

Spooky World
100 River Road
Berlin, MA 01503-1647
(978) 838-0200
1,2,3,4,6,8,11,13,14; all rides are totally accessible, received a commendation from the Surgeon General for their accessibility efforts.

MICHIGAN

Deer Acres Storybook Amusement Park
2346 M13
Pinconning, MI 48650
(517) 879-2849
1,3,4,6,11,13

Dutch Village
12350 James Street
Holland, MI 49424
(616) 396-1475
1,3,4,5,6,7,11,13,14

MINNESOTA

Anoka County Park
550 Bunker Lake Blvd.
Anoka, MN 55304
(612) 757-3920
1,3,4,6,7,11,13

Gasoline Alley
10300 Central Ave
Minneapolis, MN 55434-3669
(612) 784-race
1,3,5,6,11,13,14

Knotts Camp Snoopy
5000 Center Court
Mall of America
Bloomington, MN 55435
(612) 883-8500
1,2,3,4,5,6,7,8,11,12,13,14,15

Valleyfair
One Valleyfair Drive
Shakoppe, MN 55379-3098
(612) 445-7600
1,2,3,4,5,6,7,8,9,11,12,13,14,16

MISSISSIPPI

Funtown USA
1771 Pass Road
Biloxi, MS 39531
(601) 896-7315
1,2,3,4,6,11,14

MISSOURI

Silver Dollar City
100 Corporate Place
Branson, MO 39531
(417) 338-2611
1,2,3,4,5,6,7,11,12,13,14,15,16

World's of Fun/Oceans of Fun
4545 World of Fun Ave
Kansas City, MO 64164
(816) 454-4545
1,2,3,4,5,6,7,11,13,14; EMT's on staff

MONTANA

Big Timber Waterslide
PO Box 1374
Big Timber, MT 59011-1374
(406) 932-6570
1,3,11,13; no accessible parking spots, all rides have stairs

NEVADA

The Adventure Dome Circus
2880 Las Vegas Blvd
Las Vegas, NV 89109
(702) 794-3939
1,2,3,4,6,7,9,11,13

Buffalo Bill's Resort and Casino
PO Box 19129
Jean, NV 89019
(702) 382-1212
1,2,3,5,6,7,11,13,14,16

Ponderosa Ranch
100 Ponderosa Ranch Road
Incline Village, NV 89451-9201
(702) 831-0691
1,2,3,5,6,7,11,13,15; an outdoor gunshow with no rides

Wet 'N Wild Las Vegas
2310 Paseo Del Prado, Suite A220
Las Vegas, NV 89102
(800) 565-0786
(702) 871-7811
1,2,3,5,7,8,12,13,14,15,16; wheelchairs can be wheeled into the pools, lifeguards available to assist around the pool upon request, some staff know ASL.

THE BERENSTEIN BEARS WELC ME
VISITORS TO DORNEY PARK

Wild Island
250 Wild Island Court
Sparks, NV 89434-8946
(702) 359-2927
1,2,3,4,6,11,12,13,15; Lifeguards trained to help visitors with disabilities into and out of pools.

NEW HAMPSHIRE

Canobie Lake Park
PO Box 190
Salem, NH 03079-0190
(603) 893-3506
1,2,3,4,6,7,11,13,14,15

Story Land
Route 16
PO Box 1776
Glen, NH 03838
(603) 383-4186
1,2,3,4,5,6,7,11,12,13,14,15

Surf Coaster
Route 11B
PO Box 5368
Weirs Beach, NH 03247-5368
(603) 366-4991
1,2,4,6,11,13,15

The Whale's Tale Water Park
Route 3
PO Box 67
Lincoln, NH 03251-6488
(603) 745-8810
1,2,3,4,6,7,11,13,14

NEW JERSEY

Casino Pier and Waterworks
800 Ocean Terrace
Seaside Heights, NJ 08751-2157
(908) 793-6488
1,2,3,4,6,7,11,13,14; have sand wheelchairs available for free to get onto the beach.

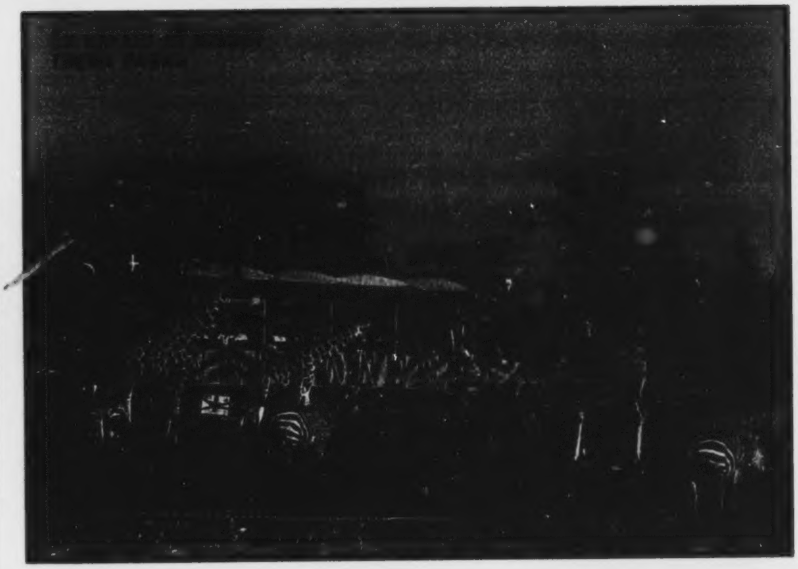
Clementon Amusement Park and Splash World
144 Berlin Road
Clementon, NJ 08021-0132
(609) 783-0263
1,2,3,4,5,6,7,11,13,14,15; ride operators trained to assist visitors on and off rides; special tubes available to use in waterpark.

Gillian's Island Water Theme Park
PO Box 1186
Ocean City, NJ 08226
(609) 399-0483
1,2,3,4,6,11,12,13,14

Land of Make Believe
Route 611 Hope Great Meadow Rd
PO Box 295
Hope, NJ 07844-0295
(908) 459-9000
1,2,3,4,5,6,11,13,14,15

Six Flags Great Adventure
Route 537-
PO Box 120
Jackson, NJ 08527-0120
(908) 928-2000
1,2,3,4,5,6,7,11,12,13,14,15,16

Storybook Land
6415 Black Horse Road
Egg Harbor Township, NJ 08234
(609) 646-0103
1,3,4,6,11,14,15



NEW YORK

Adventureland
2245 Broadhollow Road
Farmingdale, NY 08234
(516) 694-6868
1,2,3,4,6,11,13,14,15

Astroland
1000 Surf Ave
Brooklyn, NY 11244
(718) 265-2100
1,2,3,4,11,13; hosts Community Mayors of New York Day for Kids with Disabilities and their families once a year; parking on street only.

Coney Island USA
1208 Surf Ave
Brooklyn, NY 11224
(718) 372-5159
1,2,5,11; a nonprofit arts organization circus sideshow; parking on street only

Darien Lake Theme Park
9993 Allegheny Road
PO Box 81
Darien Center, NY 14040-0091
(716) 599-4641
1,2,3,4,5,6,7,8,11,12,13,14

Deno's Wonder Wheel Park
3059 West 12th Street
Brooklyn, NY 11224
(718) 372-2592
1,2,3,4,6,11,13,14

The Great Escape
Splash Water Kingdom
Route 9
PO Box 511
Lake George, NY 12845
(518) 792-3500
1,2,3,4,5,6,7,11,12,13,14,15; five to six emts a day on site

Hoffman's Playland
Route 9
Latham, NY 12110
(518) 785-3842
1,2,3,4,6,8,11,13,14

Midway Park
PO Box E
Maple Springs, NY 14756-0171
(716) 386-3165
1,2,3,4,5,6,8,11,13,14; works with Give Kids the World for a free day during the season for kids with life-threatening illnesses and their families.

Seabreeze Park
4600 Culver Road
Rochester, NY 14622-1399
(716) 323-1900
1,2,3,4,5,6,11,13,14

Sylvan Beach Amusement Park
PO Box 149
Sylvan Beach, NY 13157-0149
(315) 762-5212
1,2,3,4,6,11,13; has mobile first aid unit

NORTH CAROLINA

Emerald Pointe Water Park
391- South Holden Road
Greensboro, NC 27406
(800) 555-5900 (nc only)
(336) 852-9721
1,2,3,4,6,13,15; caregivers are admitted free

Fantasy Lake
5869 Perma Stone Drive
Hope Mills, NC 28348-2160
(910) 425-8974
1,2,3,4,5,6,11,13,14

BELOW: RIDING THE CAROUSEL AT SIX FLAGS-GREAT ADVENTURE

Ghost Town in the Sky
US Highway 19
PO Box 369
Naggie Valley, NC 28751-0369
(800) 446-7886
(704) 926-1140
1,2,3,4,5,6,11,13,14; golf carts take wheelchair users up the hill to attractions.

Jungleland
PO Box 879
Atlantic Beach, NC 28512-0879
(919) 247-2148
1,2,3,5,6,11,13,14

Paramount's Carowinds
PO Box 410289
Charlotte, NC 28241-0289
(800) 888-4fun
(704) 588-2606
1,3,4,5,6,7,11,12,13,14,15,16; assistive listening devices available upon request.

Tweetsie Railroad
PO Box 338
Blowing Rock, NC 28605-0388
(828) 264-9061
(800)526-5740
1,2,3,4,6,11,13,14,15; adult strollers available

NORTH DAKOTA

Lucy's Amusement Park
Highway 83 S.
Minto, ND 58701
(701) 839-2320
4,6,11

OHIO

Americana Amusement Park
5757 Hamilton-Middletown Road
Middletown, OH 45044
(800) 486-3070
1,3,4,5,6,7,11,13,14,15

The Beach Waterpark
2590 Waterpark Drive
Mason, OH 45040-2358
(800) 886-Swim
(513) 398-4356
1,2,3,4,6,11,13,14; have to call ahead when bringing along a guide dog.

Cedar Point
PO Box 5006
Sandusky, OH 44871-8006
(419) 626-0830
1,2,3,4,5,6,7,8,11,12,13,14

Erieview Park
5483 Lake Road
Box 310
Geneva-on-the-Lake, OH 44041-9425
(440) 466-8650
1,2,3,4,6,11,13,14,15

Paramount's Long Island
6300 Kings Island Drive
Kings Island, OH 45034
(800) 288-0808
(513) 573-5800
1,2,3,4,5,6,7,8,9,10,11,12,13,14,15

Pioneer Waterland and
Dry Fun Park
35101 Euclid Ave
Willoughboy, OH 44904
(440) 951-7227
1,2,3,4,6,7,10,11,13,15; all management and supervisory staff are trained to give CPR

Sea World of Ohio
1100 Sea World Drive
Auora, OH 44202-8700
(800) 63-shamu
(440) 562-8101
1,2,3,4,5,6,7,8,9,11,12,13,15,16

Sports City
5205 Milan Rd.
Sandusky, OH 44870
(800) 733-3353
(419) 627-1701
1,2,3,4,6,11,14;

Wyandot Lake Park
10101 Riverside Dr.
PO Box 215
Powell, OH 43065-0215
(800) 328-9283
(614) 889-9283
1,2,3,4,5,6,11,13,15

OKLAHOMA

Arbuckle Wilderness
Route 1, Bok 63
Davis, OK 73030-9801
(800) 738-PARK
(405) 369-2397
1,2,3,4,6,7,11,13,14

Sue Bo
PO Box 686
Atlus, OK 73522-0686
(580) 563-2465
1,2,3,6,11,13; bathrooms a distance away, boating attraction not wheelchair accessible.

Key to Services

1. Accessible restrooms/ drinking fountains
2. Accessible telephones
3. Accessible restaurants
4. Accessible rides/attractions
5. Accessible theaters
6. Accessible parking
7. Wheelchair rentals (manual/electric)
8. Sign language interpreters
9. Braille/audio information guides
10. Personal care services/attendants
11. Guide dogs permitted
12. Guidebooks for visitors with disabilities
13. First aid station
14. Alternate entrances for rides
15. Special ticket rates
16. Assistive listening devices

Theme-Amusement Parks

FUN IN THE SUN AT DISNEY THEME PARKS.

OREGON

Enchanted Forest
8462 Enchanted Way, SE
Turner, OR 97392
(503) 363-3060
1,2,3,4,6,10,11,13,14,15; located on a very steep hill.

Oaks Amusement Park
Southeast Oaks Parkway
Portland, OR 97202
(503) 233-5777
1,2,3,4,5,6,11,13,14,15; roller-skating rink wheelchair accessible, free day for kids with disabilities with families during the first weekend in JUne

Thrill-Ville USA
8372 Enchanted Way
Turner, OR 97392
(503) 363-4095
1,2,3,4,6,8,11,13,14

PENNSYLVANIA

Bland's Park
55 Hollywood Ave
Tipton, PA 16684-0335
(814) 684-3588
1,2,3,4,6,7,11,13,14

Bushkill Park
2125 Bushkill Park Dr.
Easton, PA 18042
(610) 258-6941
1,2,3,4,6,11,14

Dorney Park and Wildwater Kingdom
3830 Downey Park Rd.
Allentown, PA 18104-5899
(610) 395-3724
1,2,3,4,5,6,7,11,12,13,14,15

Hershey Park
100 West Hersheypark Drive
Hershey, PA 17033
(800) Hershey (437-7439)
1,2,3,4,5,6,7,10,11,12,13,14

Dutch Wonderland
2249 Route 30
Lancaster, PA 17602
(717) 291-1888
1,2,3,4,5,6,7,11,12,13,14,15

Kennywood Park
4800 Kennywood Blvd
West Miffin, PA 15122
(412) 461-0500
1,3,4,6,11,12,13,14

Knoebel's Grove Amusement Resort and Campground
PO Box 317
Elysburg, PA 17824-0317
(800) 487-4386
(717) 672-2572
1,2,3,4,5,6,7,11,13,14

Lakemont Park
700 Park Ave
Altoona, PA 16602
(814) 949-PARK (7275)
1,2,3,5,7,8,13,15,16; first aid station staffed by local hospital, no admission ride, buy as you ride

The Pennsylvania Renaissance Faire
PO Box 685
Cornwall, PA 17106-0685
(717) 665-7021
1,2,3,6,7,9,11,15; 11 stages and games of skill; some pathways are gravel

Sesame Place
100 Sesame Rd
Langhorne, PA 19407-0579
(215) 752-7070
1,2,3,4,5,6,7,10,12,13,14

Waldameer Park and Water World
220 Penisula Dr.
Erie, PA16505-0308
(814) 838-3591
1,3,4,5,6,11,13,14

Williams Grove Amusement Park
One Park Ave.
Mechanicsburg, PA 17055-5341
(717) 697-8266
1,2,3,4,5,6,11,13,14

RHODE ISLAND

The Enchanted Forest of Rhode Island
Route 3
Hope Valley, RI 02832
(401) 539-7711
1,2,3,4,6,11,13,15

SOUTH CAROLINA

Fun Spot Action and Family Entertainment Center
500 S. Ocean Blvd.
Myrtle, SC 29577-4056
(803) 448-5716
1,2,3,4,6,11,13,15; some employees trained in ASL

Myrtle Beach Pavilion Amusement Park
812 North Ocean Blvd.
Myrtle Beach, SC 29578-2095
(803) 448-6456
1,2,3,4,5,6,11,13,14,15; EMTs on staff

SOUTH DAKOTA

Flintstone's Bedrock City
West Highway 16
Custer, SD 57730
(605) 673-4073
1,2,3,4,5,6,11; all rides have ramps, first aid kits available

Wild Water West Waterpark & Family Amusement Park
26767 466th Ave
Souix Falls, SD 57104
(605) 339-2837
1,2,3,4,6,8,11,13,14,15

TENNESSEE

Dollywood
1020 Dollywood Ln.
Pigeon Forge, TN 37863-4101
(423) 428-9400
(423) 428-9488
1,2,3,4,5,6,7,11,12,13,14,15; Awareness Day for those with hearing impairments in May, September, and during the Christmas season.

Libertyland
940 Early Maxwell Blvd.
Memphis, TN 38104-5931
(901) 274-1776
1,2,3,4,5,6,7,11,12,13,14,15

TEXAS

Schlitterbahn Waterpark and Resort
305 W. Austin St.
New Barunfels, TX 78130
(210) 625-2351
1,2,3,4,5,6,10,11,12,13,14,16

Sea World of Texas
10500 Sea World Drive
San Antonio, TX 78251-3333
(210) 523-3000
1,2,3,4,5,6,7,9,11,12,13,14,15

Six Flags Astroworld/Waterworld
9001 Kirby Dr
Houston, TX 77054-2599
(713) 799-8404
1,2,3,4,5,6,7,8,11,12,13,14,15

Six Flags Fiesta Texas
PO Box 690290
San Antonio, TX 78269-0290
(800) FIE-STAT
(210) 697-5000
1,2,3,4,5,6,7,9,12,13,15,16; sign language interpreters available; can help assist visitors in planning their day.

Six Flags over Texas
PO Box 90191
Arlington, TX 76004-0191
(617) 640-8900
1,2,3,4,5,6,7,8,11,12,13,14,15

Western Playland
6900 Delta Place
El Paso, TX 79905-5510
(915) 7772-3953
1,2,3,4,6,11,13,14,15

Wonderland Amusement Park
2601 Dumas Dr.
Amarillo, TX 79105-2325
(800) 383-4712
(806) 383-4712
1,3,4,6,11,13,14

UTAH

Lagoon Amusement Park
375 N. Lagoon Dr.
Farmington, UT 84025-0696
(801) 451-8000
1,2,3,4,5,6,7,8,11,12,13,14; sign language interpreters available on request

Ya Gotta Wanna Fun Park
60 W. Cedar Ave
Moad, UT 84532
(435) 259-8007
1,2,5,7,13

VIRGINIA

Busch Gardens Williamsburg and Water Country USA
One Busch Gardens Blvd.
Williamsburg, VA 23187-8785
(757) 253-3350
1,2,3,4,5,6,7,11,12,13,14,15,16; on-staff EMT'S and registered nurses, gift shops accessible, casts roles on people who have disabilities

Paramount's Kings Dominion
PO Box 2000
Doswill, VA 23187-8785
(804) 876-5000
1,2,3,4,5,6,7,8,11,12,13,14,15,16; eatery tables with accessible design; large-print menus available.

WASHINGTON

Enchanted Village/Wild Waves
36201 Enchanted Parkway, S.
Federal Way, WA 98003-7197
(253) 925-8000
1,2,3,4,6,11,13,14

Fun Forrest
205 Harrison St., Ste 405
Seattle, WA 98109
(206) 728-1585 (info)
(206) 728-1586
1,2,3,4,6,11; once a year Seattle Parks Department hosts free rides for visitors with disabilities.

WISCONSIN

Bay Beach Amusement Park
1313 Bay Beach Road
Green Bay, WI 54301
(920) 448-3365
1,2,3,5,7,13,14,15,16

Big Chief Kart and Coaster World
PO Box 5
Wisconson Dells, WI 53965
(608) 254-2490
1,3,5,7,13,15,16

Circle M Coral Family Fun Park
10295 Highway 70 W.
Minocqua, WI 54548
(715) 356-4441
1,2,3,4,6,11,13

Extreme World
Highway 12
Wisconsin Dells Parkway
Wisconson Dells, WI 53965
(608) 254-7565
1,2,5,7,9,13,14,15,16

Little-A-Merrick-A
700 East Main St.
Marchall, WI 53559
(608) 655-3181
1,2,3,4,6,11,14

Noah's Ark Family Park
1410 Wisconsin Dells Parkway
Wisconsin Dells, WI 53965
(608) 254-6351
1,2,3,4,6,11,13,14,15

Rainbow Falls Family Park
1511 Plover Rd.
Plover, WI 54467
(800) 321-2228 (WI Only)
(715) 345-1950
1,3,4,6,11,13,14

Riverview Park and Waterworld
PO Box 300
Wisconson Dells, WI 53965-0300
(608) 254-2608
1,2,3,4,6,10,11,13; open park policy, free admission: visitors encouraged to first come in and look around to see if the rides are for them. Department supervisors will accompany visitors who have disabilities sign in braille.

Key to Services

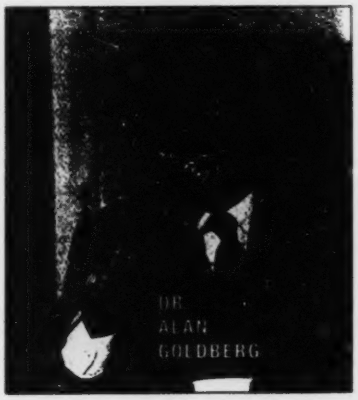
1. Accessible restrooms/ drinking fountains
2. Accessible telephones
3. Accessible restaurants
4. Accessible rides/attractions
5. Accessible theaters
6. Accessible parking
7. Wheelchair rentals (manual/electric)
8. Sign language interpreters
9. Braille/audio information guides
10. Personal care services/attendants
11. Guide dogs permitted
12. Guidebooks for visitors with disabilities
13. First aid station
14. Alternate entrances for rides
15. Special ticket rates
16. Assistive listening devices

EXCEPTIONAL PARENT'S *Exceptional People Awards*

Everyone knows someone who is exceptional in some way. We think it is fitting to honor those people who have influenced positive change in the lives of people with disabilities as an "Exceptional Person." Featured here are this year's honorees. Starting in 2000, we invite our readers to submit their nominations for Exceptional People to us for recognition throughout the year. Please send them to us at Exceptional Parent Magazine, 555 Kinderkamack Rd., Oradell, NJ 07649-1517, fax: (201) 634-6570; or e-mail epedit@aol.com.

We thank every one who participated and we especially thank those Exceptional People featured here for serving as an inspiration to everyone.

—The EP Staff



ALAN GOLDBERG

Nominated by Paul Dulle,
Executive Director,
United Cerebral Palsy of Greater Chicago

Dr. Alan Goldberg is a dad who has been an active volunteer in the movement to ensure disability rights and services. Alan has two girls, Melissa, 7, and Sarah, 11, who has cerebral palsy. As a member of his local school district's strategic planning committee, Alan helped secure the committee's input in the design of the district's special needs programming. He also worked to establish a support group for parents.

Alan has been an active board member of United Cerebral Palsy of Greater Chicago, Board President of United Cerebral Palsy of Illinois, as well as a member of the national policy-setting committee of the United Cerebral Palsy Associations. He is a Fellow of the Volunteer Leadership Institute, as well as co-chair of the Finance Committee of the Illinois Interagency Council on Early Intervention. Alan has also been appointed by the Governor to serve as chairperson of the Illinois Planning Council on Developmental Disabilities. In addition, he is a member of the New Trier Township Committee on Disabilities and a member of the Attorney General's Special Education Advisory Committee.

Thanks to the perseverance and patience of his wife, Beth, he has the time to engage in all of these community activities. Beth and Alan are deeply committed to advancing the rights and services of children and adults with disabilities.

For his personal commitment, selfless giving, and tireless dedication to the mission we all serve, Alan Goldberg is a stellar example to us all.

MICHAEL AND ANDREA GORDON

Nominated by Brookes Y. Gordon, age 16
of Lakeland, Florida

When I was 8 months old, I was diagnosed with a rare neuromuscular disease called Werdnig-Hoffman syndrome (characterized by progressive muscular weakness and atrophy). My mom and dad have gone to extreme measures to provide the most comfortable life possible for me. They are always very positive about everything, and that has helped me to just have a positive outlook on life itself. A couple of times I have had life-threatening bouts with pneumonia—actually, I was real close to death. Through all the sickness, hospital stays, and special medical needs, I could always rely on my parents. They have taught me many important life lessons. No matter how much the bills were getting behind, they still never left my side.

Although my medical needs have always been top priority for my parents, I have other wants and desires that they have met for me as well. I am a big fan of the rhythm and blues group, TLC. I went to my first TLC concert in 1993, and when I told my dad that I wanted to meet them, he managed to get me a backstage ticket. Later on that year, my parents filled out an application for The Children's Wish Foundation for me to meet and spend time with the group. My mom followed up with phone calls and two years later, my dream became reality. I was able to spend over ten hours with TLC!

Just a few months ago, my parents took me on a spur-of-the-moment trip to attend a TLC press conference in Atlanta. We usually don't do last minute things, because my medical equipment is essential, and if we forget something I could get into distress, but my parents were determined to give me this thrill.

Without having supportive parents and God, none of my desires and goals would have ever happened. I'm a big thinker, and I'm really up for challenges, so when someone doubts me, I just have to prove them wrong. This strength and determination comes from my parents always telling me that no matter what my physical limitations are, I can still achieve what ever I put my mind to. My parents, Michael and Andrea Gordon, are the true definition of EXCEPTIONAL parents.

MIKE BELLANTONI AND HIS SON ANTHONY SHOOT SOME HOOPS.

MIKE BELLANTONI

Nominated by Gail O. Olive

United Cerebral Palsy of Northeast Pennsylvania

After sustaining a life-altering spinal cord injury and completing physical rehabilitation at Allied Services, in Scranton, Pennsylvania, Mike Bellantoni moved his family to northeastern Pennsylvania and took a job as the Wheelchair Sports Coordinator for Allied Services.

Being able to participate in wheelchair sports basketball and tennis have played a crucial role in Mike's own rehabilitation and adjustment to a new lifestyle. Mike has also brought wheelchair tennis to the community, and has been instrumental in helping the Allied Forces wheelchair basketball team with their game. In addition he has also introduced a wheelchair billiards tournament to the Scranton area.

For the last nine years, Mike and his wife Betty have helped organize and run the Challenger Division Little League, a youth baseball program for children with disabilities that reaches more than 100 children. The success of the program inspired Mike and Betty to develop an innovative, indoor, adaptive soccer program at Penn State University's Worthington Campus.

The Bellantonis also started the Adaptive Sports and Recreation Foundation, and coordinated many events to raise funds and increase awareness for recreation opportunities for individuals with disabilities.

Mike serves as Board President of the Center for Independent Living. Betty serves on the Board of Directors of United Cerebral Palsy of Northeast Pennsylvania and is also the Parent-Teacher Association President at Abington Heights Middle School, Clarks Summit, Pennsylvania. Mike and Betty's son, Anthony, 11 has also gotten involved with the Challenger baseball and indoor soccer program as a "buddy."

The Deutsch Institute, a non-profit organization promoting recreational sports and pursuits for people with disabilities, honored Mike by inducting him into their Wall of Fame in 1997. Mike was also the recipient of the first Edie Ransom Award, given by the Pennsylvania Coalition for Disabilities, recognizing those who break down physical and attitudinal barriers to people with disabilities.

PATTY SPROFERA

Nominated by Linda Tempel, United Cerebral Palsy of New York City (UCP/NYC)

Born prematurely, weighing in at just 17 ounces, Patricia ("Patty") Sprofera's survival was truly a miracle. It was soon discovered that Patty had cerebral palsy, a condition that would impact her life in many ways.

After living in Germany and undergoing surgeries there, Patty returned to the US and attended New York City's first public school elementary program for children with cerebral palsy at PS 135. This also began Patty's association with UCP/NYC, the organization that would play a continuing role in her life. In 1953, she was chosen as one of three national poster children for UCP and made numerous guest appearances in that capacity.

In 1971, Patty began working with UCP/NYC as an administrative assistant in the School Division. Patty honed her listening and referral skills by assisting parents, caregivers, and agency providers. Referred to as "Colombo" (after the TV detective) by many of her colleagues, Patty had a reputation for tracking down the information that people needed and directing them to the proper resources.

After ten years, Patty moved to the staff-training department where she assisted other staff. She was forced to take a leave of absence from UCP/NYC a year later, when she underwent two spinal fusions. Told by her surgeon that she would never walk or work again, Patty defied both the odds and conventional wisdom. After spending nearly three years in body casts and having temporarily lost the use of her arms, Patty emerged victorious. She returned to work in the fall of 1986, and shortly thereafter, began working full-time in the Family Support Services department, returning to her duties at both the typewriter and phone. Patty notes, "I am happy to say that I still know what is most important and always will be—assisting families, caregivers and agencies and providing quality information to all callers." She adds, "Many people were in my corner. I truly know the meaning of 'giving back' and I am happy to do that every working day."

PATTY SPROFERA (LEFT) RECEIVES THE UCP SERVICE AWARD FROM THOMAS MAUL.

Perhaps the highlight of Patty's career came on June 17, 1997 when she was honored as an "outstanding employee" before 1,200 guests at UCP/NYC's 50th Anniversary celebration.

Over the years, many people have written letters of thanks to Patty, acknowledging her efforts on their behalf. From government and school officials to family members seeking help, the praise comes in many forms and includes words like "helpful," "superb," "diligent," "professional," and "refreshing." One mother wrote, "I couldn't believe it. She cut through all the red tape. I finally felt I had someone with an answer to my problems."

Patty is not only an inspiring role model for individuals with disabilities, she is also a woman of incredible integrity, courage, and perseverance who is a friend to many

JOSEPH PEREZ

JOSEPH PEREZ

Nominated by Catherine Hendrickson

Project Director, Day Habilitation

United Cerebral Palsy of New York City (UCP/NYC)

Joseph (Joey) Perez is 38 years old and has attended United Cerebral Palsy of New York City (UCP/NYC) for 12 years. During that time, he has exhibited impressive growth in many areas of his life.

In 1994, Joey became active in the New York State Self Advocacy Association at the NYC level. Because he did not travel independently, he found it very difficult to attend meetings that were held all over the city.

A fellow self-advocate leader, Tony Phillips, taught Joey to travel independently using city buses, Access-a-Ride and ambulette. He now travels from his home in upper Manhattan to the program in lower Manhattan, to meetings in Brooklyn and other boroughs, and by train to Albany.

His commitment to the Self Advocacy Association has deepened to the extent that in 1996, he was elected to the New York State Self Advocacy Association's board.

Joey's major advocacy project has been to improve the quality of service of Access-a-Ride, which has led him to speak at city hearings, write letters to the Manhattan Transit Authority (MTA) and help develop pick-up procedures. In addition, he has been active in motivating MTA bus drivers to use courtesy when picking up passengers in wheelchairs.

Although Joey has a very active life, he is always concerned with the well-being of others. UCP/NYC initiated a city-funded Saturday Recreation Program for adults with mental retardation/developmental disabilities. Joey volunteers as an assistant to the program director, helps with administrative tasks, and was proactive in staffing the program from its inception.

Joey is an active friend to many other people with disabilities. He volunteers to help feed participants at programs, and encourages and guides them to advocate for themselves in resolving problems. Joey, who lives with his mother, is also active with his church and uses his advocacy skills for family and neighbors, seeking necessary information and advocating for services such as building repairs.

A hard-working advocate who consistently demonstrates respect for the dignity of all people, Joey Perez is also pursuing challenging personal goals for the future, which illustrate his determination and hopeful spirit.

DARIEN BROOKS

Nominated by Kathy Kittleson

President, Very Special Arts of North Carolina

At age 4, Darien was diagnosed with autism. His disability made it difficult for him to function within his environment. He isolated himself from other people in social settings, expressed no emotional reactions, and made no eye contact. Darien was captivated, however, by reading.

Though they had been advised to have him institutionalized, Darien's parents instead decided that they could work with him. They sought help for their son from TEACCH (Treatment and Education of Autistic and Communication-related Handicapped Children), an agency based at the University of North Carolina at Chapel Hill. For years, Darien and his parents traveled weekly to Chapel Hill. His mother worked with him each night, while his father cared for his brother and sister. When he began school, he received special help from his teachers, who were supervised by the TEACCH staff.

During his childhood, Darien had some impressive accomplishments:

He taught himself to operate a manual typewriter, writing his first stories and book.

He played outfield on his church league baseball team for two years.

He signed up in the fifth grade to play his first musical instrument, a violin.

In 1985, after he graduated from high school, he matriculated at the University of North Carolina at Wilmington. There he studied music and creative writing for nearly three years. Since then, Darien has worked full-time as an office and mail clerk. He still receives services from TEACCH, in their adult program.

Darien represented North Carolina at the Very Special Arts "Art and Soul" Festival in Los Angeles, California. He lives a full life, complete with heartaches as well as highlights.

Now 33, Darien is a published author, and his interests include sports, music, books, and writing. He is nearing completion of his first novel. He has been a member of the Wilmington Symphony Orchestra for 15 years, and sings tenor in his church choir. He corresponds regularly with close friends around the world.

Darien's life is one that has set an example of courage and inspiration for everyone who knows him.

DARIEN BROOKS

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ADA Projects

Disability and Business Technical and Assistance Centers

The National Institute on Disability and Rehabilitation Research (NIDRR) of the U.S. Department of Education has established ten regional Disability and Business Technical Assistance Centers (DBTACs) to provide information, training, and technical assistance to employers, people with disabilities, and other entities with responsibilities under the Americans with Disabilities Act (ADA).

The centers act as a "one-stop" central, comprehensive resource on ADA issues in employment, public services, public accommodations, and communications. Each center works closely with local business, disability, governmental, rehabilitation, and other professional networks to provide ADA information and assistance, placing special emphasis on meeting the needs of small businesses. Programs vary in each region, but all centers provide the following:

- Technical Assistance
- Education and Training
- Materials Dissemination
- Information and Referral
- Public Awareness
- Local Capacity Building

Using this directory

Contact the DBTAC's toll-free at: **(800) 949-4232** (voice/TTY). Your call will automatically be routed to the DBTAC in your region.

This list was provided by Adaptive Environments, the New England DBTAC. When available, World Wide Web sites and e-mail addresses have been included. Web sites are listed with the standard **http://** before each. E-mail addresses are indicated by the symbol, ✉. (Unless otherwise indicated, all telephone numbers are for voice only.)

National Access for Public Schools Project

The National Access for Public Schools Project has also been funded by NIDRR to answer questions about the ADA in public schools. For information, contact Adaptive Environments, Inc., at 374 Congress St., Ste. 301 Boston, MA 02210; (800) 893-1225, Ext.28 (V/TTY). They can also be found on the Internet at http://www.adaptenv.org.

REGION 1 (CT, MA, ME, NH, RI, VT)

New England DBTAC
Adaptive Environments Center, Inc.
374 Congress Street, Ste. 301
Boston, MA 02210
(617) 695-0085 (V/TTY)
(617) 482-8099 (fax)
✉adaptive@adaptenv.org
http://www.adaptenv.org

REGION 2 (NJ, NY, PR, VI)

Northeast DBTAC
United Cerebral Palsy Associations of New Jersey
354 South Broad St.
Trenton, NJ 08608
(609) 392-4004
(609) 392-7044 (TTY)
(609) 392-3505 (fax)
✉dbtac@ucpanj.org.
http://www.disabilityact.com.

REGION 3 (DC, DE, MD, PA, VA, WV)

Mid-Atlantic DBTAC
TransCen, Inc.
451 Hungerford Dr. Ste. 607
Rockville, MD 20850
(301) 217-0124 (V/TTY)
(301) 217-0754 (fax)
✉adainfo@transcen.org.
http://www.adainfo.org.

REGION 4 (AL, FL, GA, KY, MS, NC, SC, TN)

Southeast DBTAC United Cerebral Palsy Association, Inc.
Center for Rehabilitation Technology at Georgia Tech
490 Tenth St.
Atlanta, GA 30318
(404) 385-0636 (V/TTY)
(404) 385-0641 (fax)
✉se-dbtac@mindspring.com
http://www.sedbtac.org.

REGION 5 (IL, IN, MI, MN, OH, WI)

Great Lakes DBTAC
University of Illinois/Chicago
Department on Disability & Human Development
1640 West Roosevelt Rd.
Chicago, IL 60608
(312) 413-1407 (V/TTY)
(312) 413-1856 (Fax)
✉gldbtac@uic.edu.
http://www.gldbtac.org.

REGION 6 (AR, LA, NM, OK, TX).

Southwest DBTAC
Independent Living Research Utilization
2323 South Shepherd Blvd., Ste. 1000
Houston, TX 77019
(713) 520-0232 (V/TTY)
(713) 520-5785 (fax)
✉ilru@ilru.org.
http://www.ilru.org.

REGION 7 (IA, KS, MO, NE)

Great Plains DBTAC
ADA Project
100 Corporate Lake Drive
Columbia, MO 65203
(573) 882-3600 (V/TTY)
(573) 884-4925 (Fax)
✉adalh@showme.missouri.edu.
http://www.adaproject.org.

REGION 8 (CO, MT, ND, SD, UT, WY)

Rocky Mountain DBTAC
Meeting the Challenge, Inc.
3630 Sinton Rd., Ste. 103
Colorado Springs, CO 80907
(719) 444-0268 (V/TTY)
(719) 444-0269 (fax)
✉ada-infonet@mtc-inc.com.
http://www.ada-infonet.org.

REGION 9 (AZ, CA, HI, NV, PACIFIC BASIN)

Pacific DBTAC
California Public Health Institute
2168 Shattuck Ave., Ste. 301
Berkeley, CA 94704-1307
(510) 848-2980
(510) 848-1840 (TTY)
(510) 848-1981 (fax)
✉adatech@pdbtac.com.
http://www.pacdbtac.org.

REGION 10 (AK, ID, OR, WA).

Northwest DBTAC
Washington State Governor's Committee on Disability Issues & Employment
P.O. Box 9046, MS 6000
Olympia, WA 98507-9046
(360) 438-4116 (V/TTY)
(360) 438-3208 (fax)
✉dcolley@esd.wa.gov.
http://www.wata.org/NWD.

Colleges and Universities for Students with Learning Disabilities

The selection of an appropriate college for a student with a learning disability involves the consideration of many factors. It is probably best to focus on two aspects of a school's program: the extent of services offered and the types of services available.

The extent of services describes the amount or level of help offered. Programs range from minimal to extremely comprehensive.

- A minimal support program is one that reacts to student requests, but does not anticipate their needs. Such a program is appropriate for an independent self-advocate who knows what he or she needs and can request it.
- The next type of program is a moderate support program. This type offers additional features, such as learning strategies instruction, counseling, and content tutoring. There is usually a learning disability specialist available to advise students. This type of program is good for students who want a mainstream environment, but need specific support.
- A fully integrated, comprehensive program is typified by a coordinated array of services offered to each student at enrollment. Services address psychological, academic, and social needs. Students are often required to participate in specific parts of the program.
- A comprehensive program may benefit a student who has difficulty anticipating needs, or who wants a more structured environment.

Type of service refers to the philosophy that governs the program. Types of services include:

- remedial,
- psychoeducational, or
- compensatory.

Remedial services focus on re-learning needed academic skills, placing emphasis on solidifying basic skills. Psychoeducational services concentrate on counseling and using social/emotional support as a supplement to academic assistance.

Compensatory services teach coping techniques and strategies to help students work "around" their disabilities and find effective academic alternatives—Excerpted from "Striking the Match," by Georgeann duChossois, EdM EP, September 1999, p.77.

The following is a subjective list but by no means an exhaustive one, of college programs categorized by type and extent of services for students with learning disabilities. These categories are mostly a continuum of services and there is some overlap. This list was compiled by Georgeann duChossois EdM, (as indicated by the red type). Additional entries were provided by Rhoda Cummings, EdD, and Cleborne D. Maddux, PhD (as indicated by the blue type).

Georgeann duChossois, EdM, is in private practice in the NY/NJ area. She specializes in college advisement and learning disabilities assessments for adolescents and adults. She can be contacted via e-mail at duchossois@earthlink.net.

Rhoda Cummings PhD is Professor of Counseling and Educational Psychology at the University of Nevada, Reno and the mother of a son with learning disabilities.

Cleborne D. Maddux, PhD is Professor of Counseling and Educational Psychology at the University of Nevada, Reno. He received his doctorate in learning disabilities at the University of Arizona.

EXTENT OF SERVICES

Comprehensive—maximum level of support usually characterized by an integrated program of services in which all students participate—sort of a package deal for the students.

Adelphi University
Office of Disability Support Services
Attn: Joyce George
310 University Center
South Avenue
Garden City, NY 11530
(800) ADELPHI

Beacon College
105 East Main St.
Leesburg, FL 34748
(352) 787-7660

Curry College
Disability Services
Attn: Dr. Tom Byrne
Counseling Services
Milton, MA 02186
(617) 333-2120

Fairleigh-Dickinson University
Grace Hottinger
4111 River Rd.; T-200B
Teaneck, NJ 07666
(201) 692-2089

Landmark College
*exclusively for students with LD
Landmark College; RR1
Box 1000
Putney, VT 05346
(802) 387-4767

University of Arizona
Center for Disabilities
Attn: Sue Kroeger
1540 East 2nd St.
PO Box 210064
Tuscon, AZ 85721
(520) 626-7674

Decentralized—minimal level of services necessary to comply with ADA and 504 is offered—appropriate for students with strong self-advocacy skills, high degree of academic experience.

Ferris State University
Career Center
42 Oak St.
Big Rapids, MI 49307-2020
(231) 591-2685

Hobart and William Smith Colleges
Center for Academic Support Services
Attn: Joyce Dillon, (CASS)
Geneva, NY 14456-3379
(800) 852-2256

Johns Hopkins University
Attn: Ms. Evan Theodore
3400 Charles ST.
Baltimore, MD 21218
(410) 516-8174

Mansfield University of Pennsylvania
516 North Hall
Mansfield, PA 16933
(570) 662-4930
(570) 662-4109 (fax)

Plymouth State College
Counseling and Human Relations
17 High St.
Mail Service Center #26
Plymouth, NH 03264
(603) 535-2461
(603) 535-2391 (fax)

Swarthmore College
Attn: Myrt Westphal
500 College Ave.
Swarthmore, PA 19081
(610) 328-8000

University of California, Berkley
Department of Disabled Students
230 Cesar East Chavez
(Student Center)
Building 4250
Berkley, CA 94720-4250
(510) 642-0518

University of Kentucky
Career Center
201 Mathews Building
Lexington, KY
(606) 257-2746

Wharton
Office of Affirmative Action and Equal Opportunities
Attn: Alice Nagle
Ste. 228; Sansom Place East
3600 Chestnut St.
Philadelphia, PA 19104-6106
(215) 898-6993

Colleges and Universities for Students with Learning Disabilities

EXTENT OF SERVICES

Centrally-coordinated—moderate level of support with, at least, a part-time LD specialist. Usually students construct a program of services to suit their needs from a "menu" of available options.

California State University, San Bernardino
5500 University Pkwy
San Bernardino, CA 92407
(909) 880-5000
Community College of Denver
Student Development
P.O. Box 173363
Campus Box 400
Denver, CO 80217-3363
(303) 556-3300
(303) 556-3898 (fax)
Hofstra University, PHED
Davison Hall, Room 202
110 Hofstra University
Hempstead, NY 11549
(516) 463-6600
Iowa State University
Office of Admissions
Alumni Hall
Ames, IA 50011-2010
(515)-294-5836/
(800) 262-3810
(515) 294-3094 (TTY)
(515) 294-2592 (fax)
✉admissions@iastate.edu

Lesly College
29 Everett St.
Cambridge, MA 02138-2790
(617) 349-8300
(800) 999-1959
(Ask about the Threshold Program)
University of California, Los Angeles, UCLA
Office for Students with Disabilities
PO Box 951426
Murphy Hall A-255
405 Hilgard Ave.
Los Angeles, CA 90095-1426
(310) 825-1501
University of Connecticut, Storrs
Center for Students with Disabilities
Attn: Donna M. Korbel
Wilbur Cross Building, Room 231
233 Glenbrook Rd., U-174
Storrs, CT 06269-4174
(806) 486-2020

University of Denver
2199 South University Blvd.
Denver, CO 80208
Phone: (303) 871-2000
(800) 525-9495 (303) 871-3300 (fax)
✉admission@du.edu
University of Georgia
Disability Services
Attn: Lisa David; Clark Howell Hall
University of Georgia
Athens, GA 30602
(706) 542-8719
University of Massachusetts, Boston
Ross Center for Disability Services
Attn: Donna Guiliana
100 Morrissey Blvd.
Boston, MA 02125-3393
(617) 287-7430

University of Massachusetts, Dartmouth
Admissions Office
285 Old Westport Rd.
West Dartmouth, MA 02747-2300
(508) 999-8605 (508) 999-8755 (fax)
✉admissions@umassd.edu
University of North Carolina at Chapel Hill
Office of Undergraduate Admission
CB #2200 Jackson Hall
University of North Carolina at
Chapel Hill
Chapel Hill, NC 27599
(919) 966-3621
(919) 962-3045 (fax)
✉uadm@email.unc.edu
University of Texas at Austin
Freshman Admission Center
John Hargis Hall; UT-Austin
Austin, TX 78712
(512) 475-7440
(512) 475-7475 (fax)
✉frmn@uts.cc.utexas.edu

TYPE OF SERVICES

Remedial—focus on relearning needed academic skills and emphasize solidifying basic skills.

Beacon College
105 East Main Street
Leesburg, FL 34748
(352) 787-7660
Iowa State University
Office of Admissions, Alumni Hall
Ames, IA 50011-2010
(515)-294-5836 (800) 262-3810
(515) 294-3094 (TTY) (515) 294-2592 (fax)
✉admissions@iastate.edu

Landmark College
*exclusively for students with LD
Landmark College; RR1
Box 1000
Putney, VT 05346
(802) 387-4767

University of Massachusetts, Dartmouth
Admissions Office
285 Old Westport Rd.
West Dartmouth, MA 02747-2300
(508) 999-8605
(508) 999-8755 (fax)
✉admissions@umassd.edu

University of Wisconsin, Oshkosh
Project Success
Attn: Dr. Bill Kitz
800 Algoma Blvd.
Oshkosh, WI 54901-8602
(920) 424-1033

Psychoeducational—emphasis on counseling and social/emotional support as supplement to academic assistance.

Adelphi University
Office of Disability Support Services
Attn: Joyce George
310 University Center
South Avenue
Garden City, NY 11530
(800) ADELPHI

Lynn University
Human Resources
Attn: Angela Juliano
3601 North Military Trail
Boca Raton, FL 33431-5598
(561) 237-7853

Southern Illinois University, Carbondale
Human Resources
Attn: Vernola Sumner
805 South Elizabeth
Carbondale, IL 62901
(618) 453-6668

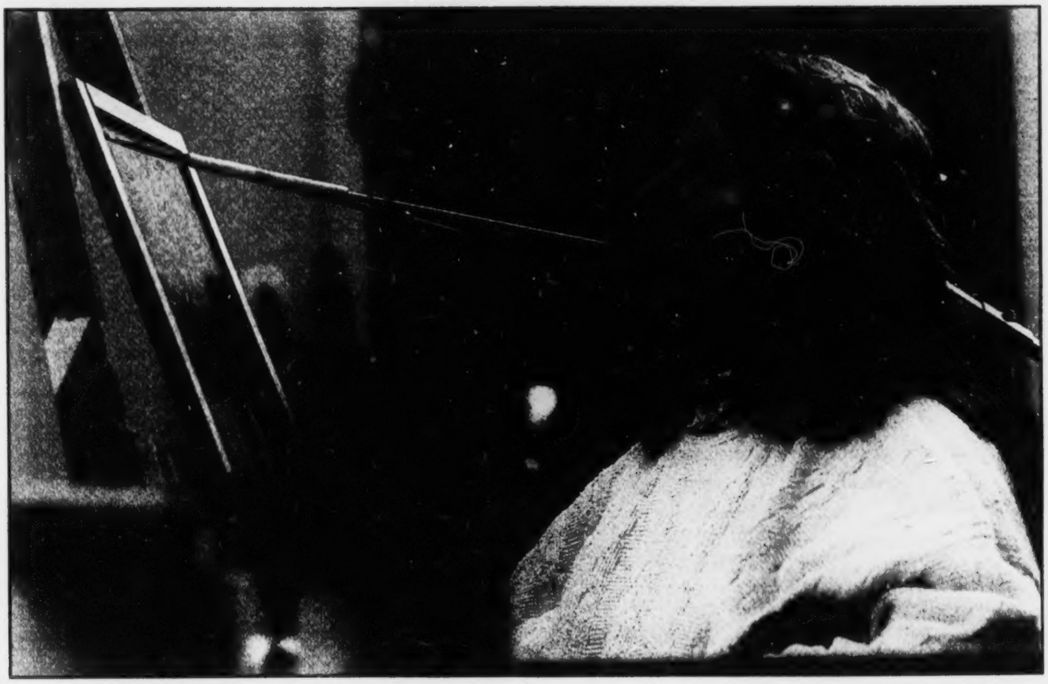
Compensatory—emphasis on coping techniques and strategies using current coursework and academic requirements.

American University
Disability Support Services
120 Mary Graydon Center
4801 Massachusetts Avenue NW
Washington, DC 20016
(202) 885-3315
California State University, San Bernardino
5500 University Pkwy
San Bernardino, CA 92407
(909) 880-5000
Community College of Denver
Student Development
P.O. Box 173363
Campus Box 400
Denver, CO 80217-3363
(303) 556-3300
(303) 556-3898 (fax)

Ferris State University
Career Center
42 Oak St.
Big Rapids, MI 49307-2020
(231) 591-2685
Mansfield University of Pennsylvania
516 North Hall
Mansfield, PA 16933
(570) 662-4930
(570) 662-4109 (fax)
Oregon State University
Services for Students with Disabilities
Kerr Administration
Attn: Tracey Bentley-Townlin
Corvallis, OR 97331-2133
(541) 737-4098
University of Colorado
Disability Services
Attn: Terri Bodhaine
Campus Box 107
Boulder, CO 80309
(303) 492-8671

University of Connecticut, Storrs
Center for Students with Disabilities
Attn: Donna M. Korbel
Wilbur Cross Building, Room 231
233 Glenbrook Road, U-174
Storrs, CT 06269-4174
(806) 486-2020
University of Denver
2199 South University Blvd.
Denver, CO 80208
(303) 871-2000 (800) 525-9495
(303) 871-3300 (fax)
✉admission@du.edu
University of North Carolina at Chapel Hill
Office of Undergraduate Admission
CB #2200 Jackson Hall
University of North Carolina at
Chapel Hill
Chapel Hill, NC 27599
(919) 966-3621(919) 962-3045 (fax)
✉uadm@email.unc.edu

University of Texas at Austin
Freshman Admission Center
John Hargis Hall; UT-Austin
Austin, TX 78712
(512) 475-7440
(512) 475-7475 (fax)
✉frmn@uts.cc.utexas.edu
University of Vermont
Office of Specialized Student Services
Attn: Nancy Oliker
A-170 Living and Learning Center
Burlington, VT 05405-0386
(802) 656-7753
Washington University
Disabled Student Service Office
Dyane Haynes
448 Schmitz Hall
PO Box 355839
Seattle, WA 98195
(206) 543-8924



Spring Time by Amy Neubauer

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NAIS
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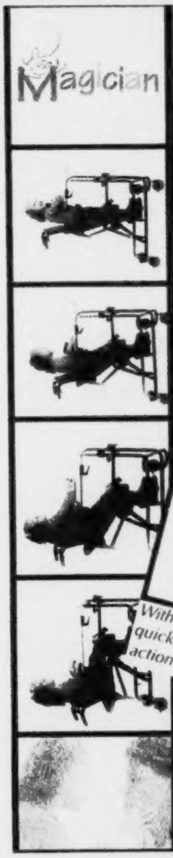

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► Taylor, George—**CURRICULUM MODELS AND STRATEGIES FOR EDUCATING INDIVIDUALS WITH DISABILITIES IN INCLUSIVE CLASSROOMS.** '99, 260 pp. (7 x 10), 20 tables, $48.95, cloth, $35.95, paper.

► Boriss-Krimsky, Carolyn—**THE CREATIVITY HANDBOOK: A Visual Arts Guide for Parents and Teachers.** '99, 186 pp. (7 x 10), 57 il., $38.95, cloth, $26.95, paper.

► Levison, Lorie & Isabelle St. Onge—**DISABILITY AWARENESS IN THE CLASSROOM: A Resource Tool for Teachers and Students.** '99, 230 pp. (7 x 10), 35 il. (and a separate packet of 35 photo cards in a 5 1/2" x 8 1/2" size), $38.95 spiral (paper).

► Gandy, Gerald L., E. Davis Martin, Jr. & Richard E. Hardy—**COUNSELING IN THE REHABILITATION PROCESS: Community Services for Mental and Physical Disabilities. (2nd Ed.)** '99, 358 pp. (7 x 10), 9 il., $57.95, cloth, $44.95, paper.

Rose, Harriet Wallace—**SOMETHING'S WRONG WITH MY CHILD! A Valuable Resource in Helping Parents and Professionals to Better Understand Themselves in Dealing with the Emotionally Charged Subject of Children with Disabilities. (2nd Ed.)** '98, 234 pp. (7 x 10), $46.95, cloth, $33.95, paper.

Hollis, James N.—**CONDUCTING INDIVIDUALIZED EDUCATION PROGRAM MEETINGS THAT WITHSTAND DUE PROCESS: The Informal Evidentiary Proceeding.** '98, 180 pp. (7 x 10), $41.95, cloth, $28.95, paper.

Cowden, Jo E., L. Kristi Sayers, & Carol C. Torrey—**PEDIATRIC ADAPTED MOTOR DEVELOPMENT AND EXERCISE: An Innovative, Multisystem Approach for Professionals and Families**. '98, 346 pp. (7 x 10), 183 il., 9 tables, $66.95, cloth, $53.95, paper.

Nevil, Nevalyn F., Marna L. Beatty, and David P. Moxley—**SOCIALIZATION GAMES FOR PERSONS WITH DISABILITIES: Structured Group Activities for Social and Interpersonal Development**. '97, 176 pp. (7 x 10), 1 il., $45.95, cloth, $32.95, paper.

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Plumridge, Diane M., Robin Bennett, Nuhad Dinno & Cynthia Branson—**THE STUDENT WITH A GENETIC DISORDER: Educational Implications for Special Education Teachers and for Physical Therapists, Occupational Therapists, and Speech Pathologists**. '93, 382 pp. (7 x 10), 32 il., 8 tables, $79.95, cloth, $47.95, paper.

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Lombana, Judy H.—**GUIDANCE FOR STUDENTS WITH DISABILITIES. (2nd Ed.)** '92, 198 pp. (7 x 10), 1 table, $50.95, cloth, $34.95, paper.

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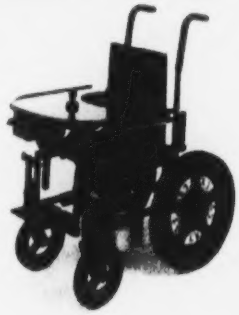

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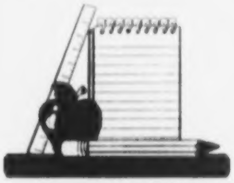

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135

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Early Intervention Directory

The Individuals with Disabilities Education Act (IDEA) requires all states and territories to provide early intervention and preschool special education for children with disabilities and special healthcare needs. When available, this directory lists these resources for each state or territory:

- Central Directory (**CD**) telephone numbers: For families and professionals seeking information about early intervention and other public and private resources for young children, this number is a good place to start. Many toll-free CD numbers are for in-state use only.
- Chairpersons of Interagency Coordinating Councils (**ICC**): ICCs include representatives of agencies, service providers, and families. Their role is to advise and provide assistance on early intervention programs and, in some states, preschool services as well.
- Coordinators of infant and toddler programs serving children from birth to age three are known as **Part C** programs.
- Coordinators of preschool special education programs (known as **619** programs) serving children from ages three through five.

These listings are provided by the National Early Childhood Technical Assistance Center (NECTAS, Frank Porter Graham Child Development Center, University of North Carolina at Chapel Hill, Ste. 500, 137 E. Franklin St., Chapel Hill, NC 27514; (919) 962-2001; (919) 966-4041 (TTY); (919) 966-7463 (fax) ✉ nectas@unc.edu, and are current as of November 1999. This information is also available on the NECTAS Web site: **http://www.nectas.unc.edu** and is updated on a monthly basis.

Using This Directory

When available, World Wide Web sites and e-mail addresses have been included. Web sites are listed with the standard **http://** before each. E-mail addresses are indicated by the symbol, ✉. (Unless otherwise indicated, all telephone numbers are for voice only.)

ALABAMA

CD: (800) 543-3098
✉skar[illegible]nika@rehab.state.al.us

ICC: Joseph Busta, ICC Chair
AL Institute for the Deaf and Blind
PO Box 698
Talladega, AL 35160
(205) 761-3200
(205) 761-3344 (fax)

Part C: Ouida Holder, Part C Coordinator
Early Intervention Prog.
2129 East South Blvd.
PO Box 11586
Montgomery, AL 36111-0586
(334) 613-2393
(334) 613-3541 (fax)
http://www.rehab.state.al.us/intervention.html
✉oholder@rehab.state.al.us

619: James Waid, 619 Coordinator
Prog. for Exceptional Children
State Dept. of Ed.
Gordon Persons Building, Rm 3346
PO Box 302101
Montgomery, AL 36130-2101
(334) 242-8114
(334) 242-9192 (fax)
✉jwaid@sdenet.alsde.edu

ALASKA

CD: (800) 478-2221
http://www.ak.org/
✉jhuangli@alaska.net

ICC: Kris Johnston, ICC Chair
PO Box 1729
Cordova, AK 99574
(907) 424-3145
✉kris@ptialaska.net

ICC: Lori Walter, ICC Chair to EI Committee
PO Box 35397
Fort Wainwright, AK 99703-0397
(907) 488-4709
✉glwalter@ptialaska.net

Part C: Jane Atuk, Part C Coordinator
Maternal and Child Health
State Dept. Health and Social Svcs
1231 Gambell St.
Anchorage, AK 99501-4627
(907) 269-3419
(907) 269-3465 (fax)
✉jane_atuk@health.state.ak.us

619: Wendy Tada, Coordinator
State Dept. of Ed.
801 West Tenth St., Ste. 200
Juneau, AK 99801-1894
(907) 465-2970
(907) 465-2806 (fax)
✉wendy_tada@educ.state.ak.us

AMERICAN SAMOA

CD: (684) 633-4929

ICC: Matt Tunoa, ICC Chair
LBJ Tropical Medical Center
American Samoa Hospital Authority
Government of American Samoa
Pago Pago, AS 96799
(684) 633-4929
(684) 633-2167 (fax)

Part C: Julia Lyons, Part C Coordinator
Dept. of Health
Government of American Samoa
Pago Pago, AS 96799
(684) 633-4929
(684) 633-2167 (fax)

619: Preschool Coordinator
Special Ed. , Dept. of Ed.
PO Box 434
Pago Pago, AS 96799
(684) 633-1323
(684) 633-4240 (fax)

ARIZONA

CD: (800) 232-1676

ICC: Ginger Mach-Ward, ICC Co-Chair
Southwest Human Development, Inc.
202 East Earll, Ste. 140
Phoenix, AZ 85012
(602) 266-5976
✉gward@swhd.org

ICC: Annabel Rose, ICC Co-Chair
The Blake Foundation
Children's Achievement Center
3825 East Second St
Tucson, AZ 85716
(520) 325-0611
(520) 327-5414 (fax)

Part C: Molly Dries, Part C Coordinator & Executive Director
Arizona Early Intervention Prog.
Dept. of Economic Security
1717 West Jefferson, SC 801A-6
Phoenix, AZ 85007
(602) 542-5463
(602) 542-5339 (fax)
✉vomm5793@de.state.az.us

619: Linda Shields, 619 Coordinator
Division of Special Ed.
Arizona Dept. of Ed.
1535 West Jefferson St.
Phoenix, AZ 85007
(602) 542-4013
(602) 542-5404 (fax)
✉lshield@mail1.ade.state.az.us
http://www.state.az.us/

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✉dds1@aristotle.net

ICC: Ruth Castlebury, ICC Chair
PO Box 10508
Conway, AR 72033
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(501) 329-2113 (fax)

Part C: Sherrill Archer, Interim Part C Coordinator
DD Svcs , Dept. of Human Svcs
Donaghey Plaza North
7th and Main Streets
PO Box 1437, Slot 2520
Little Rock, AR 72203-1437
(501) 682-8699
(501) 682-8687 (fax)
✉sherrill.archer@mail.state.ar.us

619: Sandra Reifeiss, Coordinator
Special Ed. Section
State Dept. of Ed.
#4 Capitol Mall, Rm 105-C
Little Rock, AR 72201
(501) 682-4225
(501) 682-5168 (fax)
✉sreifeiss@arkedu.k12.ar.us

CALIFORNIA

CD: (800) 515-2229
http://www.dds.cahwnet.gov/servov.htm

ICC: Raymond M. Peterson, ICC Chair
San Diego-Imperial Counties Development Svcs , Inc.
4355 Ruffin Rd., Ste. 206
San Diego, CA 92123-1648
(619) 576-2932
(619) 576-2873 (fax)

Part C: Julie Jackson, Acting Part C Coordinator
Early Intervention Prog.
Dept. of Developmental Svcs
1600 9th St., Rm 310
PO Box 944202
Sacramento, CA 95814
(916) 654-2716
(916) 654-3255 (fax)
http://www.dds.ca.gov/prev004.htm
✉jjackso1@dds.ca.gov

619: Walter Olsen, 619 Coordinator
Special Ed. Division
State Dept. of Ed.
515 L St., Ste. 270
Sacramento, CA 95814
(916) 327-4216
(916) 327-3706 (fax)
✉wolsen@cde.ca.gov

COLORADO

CD: (303) 866-6710
http://www.dooronline.org/
✉chelius_d@cde.state.co.us

ICC: Sandra Scott, ICC Co-Chair
1808 Centennial Rd.
Fort Collins, CO 80525
(970) 229-0224
(970) 266-1344 (fax)
✉coachsys@earthlink.net

ICC: Steven Smetak, ICC Co-Chair
9051 Hoyt St.
Westminster, CO 80021
(303) 423-1012
(303) 403-4410 (fax)
✉sasmetak@dnvr.uswest.net

Part C: Susan Smith, Part C Coordinator
Prevention Initiatives
Colorado Dept. of Ed.
201 East Colfax Ave., Rm 301
Denver, CO 80203
(303) 866-6709
(303) 866-6662 (fax)
✉smith_s@cde.state.co.us

619: Jane L. Amundson, 619 Coordinator
Prevention Initiatives
Early Childhood Initiatives
Colorado Dept. of Ed.
201 East Colfax Ave., Rm 305
Denver, CO 80203-1799
(303) 866-6712
(303) 866-6662 (fax)
✉Amundson_J@cde.state.co.us

CONNECTICUT

CD: (800) 505-7000
http://www.birth23.org/
✉kareena@ctunitedway.org

ICC: Connie Elmore, ICC (parent)
66 Woodbury Hill
Woodbury, CT 06798
(203) 263-6813

Part C: Linda Goodman, Part C Coordinator
Birth to Three System
Dept. of Mental Retardation
460 Capitol Ave.
Hartford, CT 06106-1308
(860) 418-6147
(860) 418-6003 (fax)
✉linda.goodman@po.state.ct.us
http://www.birth23.org/

619: Maria Synodi, 619 Coordinator
State Dept. of Ed.
25 Industrial Park Rd.
Middletown, CT 06457
(860) 807-2054
(860) 807-2062 (fax)
✉maria.synodi@po.state.ct.us

DELAWARE

CD: (800) 464-4357
✉rcabelli@state.de.us

ICC: Beth MacDonald, ICC Chair
35 West Fairfield Dr.
Dover, DE 19901
(302) 697-1976
(302) 698-1778 (fax)
✉bmacdon@den.k12.de.us

Part C: Rosanne Griff-Cabelli, Part C Coordinator
Division of Management Svcs
Dept. of Health and Social Svcs
1901 North Dupont Highway, Rm 204
New Castle, DE 19720
(302) 577-4647
(302) 577-4083 (fax)
✉rcabelli@state.de.us

619: Martha Toomey, 619 Coordinator
Dept of Public Instruction
Townsend Building
PO Box 1402
Dover, DE 19903-1402
(302) 739-4667
(302) 739-2388 (fax)
✉mtoomey@state.de.us

DISTRICT OF COLUMBIA

CD: (202) 727-8300

ICC: Tawara Goode, ICC Chair
Child Development Center
Georgetown University
3307 M St. NW, Ste. 401
Washington, DC 20007
(202) 687-8635
(202) 687-8899 (fax)

Part C: Joan Christopher, Part C Coordinator
DC-EIP Svcs
609 H St. NE, 5th Fl.
Washington, DC 20002
(202) 727-5930
(202) 727-5971 (fax)

BUREAU OF INDIAN AFFAIRS

619: Ken Whitehorn, Chief
Branch of Exceptional Ed.
Bureau of Indian Affairs
MS 3512, MIB-Code 523
1849 C St. NW
Washington, DC 20240-4000
(202) 208-4975
(202) 273-0030 (fax)

619: Bernadette Quinn, 619 Coordinator
DC Public Schools, 6th Fl
825 North Capitol St. NE
Washington, DC 20002
(202) 442-5496
(202) 442-5518/5517 (fax)

FLORIDA

CD: (800) 654-4440
http://www.centraldirectory.org/
✉lalong@centraldirectory.org

ICC: Katherine Kamiya, ICC Chair
Florida's Collaboration for Young Children and Their Families
Head State-State Collaboration Office
1310 Cross Creek Circle, Ste. A
Tallahassee, FL 32301
(850) 487-8871
(850) 487-0045 (fax)
✉kkamiya@com1.med.usf.edu

Part C: Janet Evans, Co-Coordinator
Early Intervention Unit
Children's Medical Svcs
Dept. of Health
2020 Capital Circle SE, BIN # A06
Tallahassee, FL 32399-1700
(850) 487-2690
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✉janet_h_evans@dcf.state.fl.us

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Dept. of Health
2020 Capital Circle SE, BIN # A06
Tallahassee, FL 32399-1700
(850) 487-2690
(850) 488-3813 (fax)
✉janice_kelley@dcf.state.fl.us

619: Carole West, Coordinator
Division of Public Schools
Dept. of Ed. and Community Svcs
325 West Gaines St., Rm 614
Tallahassee, FL 32399-0400
(850) 488-1106
(850) 922-7088 (fax)
✉westc@mail.doe.state.fl.us

GEORGIA

CD: (800) 229-2038
http://www.parenttoparentofga.org/home.htm
✉info@parenttoparentofga.org

ICC: Walter Black, CICC Chair
5097 Vixen Court
Acworth, GA 30101
(770) 975-1173
✉walterblack@mindspring.com

Part C: Wendy Sanders, Coordinator
Babies Can't Wait Prog.
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619: Toni Waylor Bowen, 619 Coordinator
Dept. for Exceptional Students
State Dept. of Ed.
1870 Twin Towers East
Atlanta, GA 30334-5010
(404) 657-9955
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✉tbowen@doe.k12.ga.us

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CD: (617) 475-0549

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790 Gov Carlos Camacho Rd.
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Columbus, OH 43215-4183
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(614) 728-2338 (fax)

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http://oasis.ouhsc.edu/

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(405) 789-1662 (fax)

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Oklahoma City, OK 73105-4599
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(405) 522-3503 (fax)
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(541) 346-2636 (fax)
✉jrtn@oregon.uoregon.edu

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State Dept. of Ed.
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(503) 373-7968 (fax)
✉jane.mulholland@ode-exl.ode.state.or.us

619: Nancy Johnson-Dorn, 619 Coordinator
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State Dept. of Ed.
Public Service Building
255 Capitol St. NE
Salem, OR 97310-0203
(503) 378-3598 Ext. 625
(503) 373-7968 (fax)
http://www.ode.state.or.us/
✉nancy.johnson-dorn@state.or.us

PALAU

CD: (680) 488-2537

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Special Ed. Advisory Council
Republic of Palau
PO Box 716
Koror, Palau, PW 96940
(680) 488-2318
(680) 488-1211 (fax)

Part C: Elizabeth Watanabe, Coordinator
Part C Prog.
Bureau of Ed.
Republic of Palau
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(680) 488-2537
(680) 488-2830 (fax use 011)

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Republic of Palau
PO Box 278
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(680) 488-2830 (fax)

PENNSYLVANIA

CD: (800) 692-7288
✉connect@southstar.org

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Harrisburg, PA 17109
(717) 540-4722
(717) 540-7603 (fax)
✉parent2parent@southstar.org

Part C: Maureen Cronin, Acting Part C Coordinator
Div of Early Intervention Svcs
Office of Mental Retardation
Dept. of Public Welfare
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(717) 787-6583 (fax)
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Dept. of Ed.
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(717) 783-6139 (fax)

619: Richard Price, Director
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POHNPEI

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Dept. of Health, Ed. and Social Affairs
PO Box PS87, Pohnpei State
Palikir, Pohnpei, FM 96941
(691) 320-2302
(691) 320-5500 (fax)

PUERTO RICO

CD: (787) 763-4665
✉nperez@salud.gov.pr

ICC: Ana Navarro, ICC Chair
Calle Francisco Sein #503
Floral Park
Hato Rey, PR 00917
(787) 759-6546
(787) 759-6719 (fax)

Part C: Naydamar Perez de Otero, Coordinator
Part C Prog.
Dept. of Health
Office of the Secretary
Call Box 70184
San Juan, PR 00936
(787) 274-5659
(787) 274-3301 (fax)

619: Myrta Reyes, Director for Early Childhood
Special Ed. Programs
GPO Box 759
Hato Rey, PR 00919
(787) 759-7228
(787) 753-7691 (fax)

RHODE ISLAND

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The Rhode Island Arc
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Cranston, RI 02920
(401) 463-9191
(401) 463-9244 (fax)

Part C: Ron Caldarone, Part C Coordinator
Rhode Island Dept. of Health
Div.of Family Health
Cannon Building, Rm 302
3 Capitol Hill
Providence, RI 02908-5097
(401) 222-4612 Ext. 112
(401) 222-1442 (fax)
http://www.health.state.ri.us/

619: Amy Cohen, Preschool Grant Coordinator
Office Integrated Social Svcs RI DOE
Shepherd Building
255 Westminister Rd.
Providence, RI 02903-3400
(401) 222-4600 Ext. 2408
(401) 222-4979 (fax)
✉abcohen@ride.ri.net

SOUTH CAROLINA

CD: (800) 922-1107
✉deniser@cdd.sc.edu
http://www.cdd.sc.edu/scsis

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Rock Hill, SC 29733
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(803) 323-2585 (fax)
✉duckworths@winthrop.edu

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Div.of Community Health Svcs
Dept. of Health and Environmental Control
Robert Mills Complex, Box 101106
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(803) 898-0389 (fax)
✉hartkf@columb61.dhec.state.sc.us

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✉barb.hemmelman@state.sd.us

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School of Medicine
414 E. Clark St.
Vermillion, SD 57069
(605) 677-5311
(605) 677-6274 (fax)
✉jwounded@usd.edu

Part C: Barb Hemmelman, Ed. Prog. Asst. Manager
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700 Governors Dr.
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(605) 773-6846 (fax)
✉barb.hemmelman@state.sd.us

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Dept. of Ed. and Cultural Affairs
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(605) 773-6847 (fax)
✉sharon.hoelscher@state.sd.us

TENNESSEE

CD: (800) 852-7157
✉bbledsoe@mail.state.tn.us

ICC: Wesley Brown, ICC Chair
Center for Early Childhood
East Tennessee State University
920 West Maple St.
Box 70720
Johnson City, TN 37614-0720
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(423) 439-5624 (fax)
✉wesbrown@etsu.edu

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State Dept. of Ed.
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(615) 532-9412 (fax)
✉dmattraw@mail.state.tn.us

TEXAS

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✉mskolnik@eci.state.tx.us
http://www.eci.state.tx.us/

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3106 Palmer
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Part C: Mary Elder, Executive Director
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Brown-Heatly State Office Building
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UTAH

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✉accessut@state.ut.us
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Parent Educ Advocacy Train Ctr (PEATC)
10340 Democracy Ln., Ste. 206
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(703) 691-7826
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PO Box 1797
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WASHINGTON

CD: (800) 322-2588
http://www.wa.gov/dshs/iteip/iteip.html

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http://wind.uwyo.edu/pathways/index.htm

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Federal & Federally Funded Information Resources

The federal government supports many clearinghouses, information centers, and institutes that focus on specific topics. In addition to publishing and distributing extensive free material on disability-related subjects, many of the clearinghouses, centers, and institutes also provide referrals to local resources. Staff and funding vary. Because of small staff, several clearinghouses have asked that their phone numbers not be listed; though they are happy to respond to written—and sometimes faxed or e-mailed—requests for information.

For more information on federal and federally-funded information resources, contact:

- **NICHCY** (National Information Center for Children and Youth with Disabilities), PO Box 1492, Washington, DC 20013-1492; (800) 695-0285 (voice, TTY); (202) 884-8441 (fax).
- **NARIC** (National Rehabilitation Information Center), 8455 Colesville Rd., Ste. 935, Silver Spring, MD 20910; (800) 346-2742 (voice), (301) 588-9284 (voice, TTY); (301) 587-1967 (fax).
- **NHIC** (National Health Information Center), PO Box 1133, Washington, DC 20013-1133; (800) 336-4797 (voice); (301) 984-4256 (fax).

When available, World Wide Web site and e-mail addresses have been included. Web sites include the standard **http://** before each address. E-mail addresses are indicated by the symbol, ✉. (Unless otherwise indicated, all telephone numbers are for voice only.)

ACCESSIBILITY

The Access Board
1331 F. St., NW #1000
Washington, DC 20004-1111
(800) 872-2253 (voice)
(800) 993-2822 (TTY)
(202) 272-5447 (fax)
✉info@access-board.gov
http://www.access-board.gov

AIDS

CDC National Prevention Information Network
PO Box 6003
Rockville, MD 20849-6003
(800) 458-5231 (voice)
(800) 243-7012 (TTY)
(301) 562-1098 (international line)
(888) 282-7681 (fax)
✉info@cdcnac.org
http://www.cdcnpin.org

National AIDS Hotline
c/o American Social Association
PO Box 13827
RTP, NC 27709
(800) 342-2437 (English)
(800) 344-7432 (Spanish)
(800) 243-7889 (TTY)
(919) 361-4855 (fax)
http://www.sunsite.unc.edu/asha

ALLERGY & INFECTIOUS DISEASES

National Institute of Allergy & Infectious Diseases
Office of Communication and Public Liason
Bldg 31, Rm 7A50
31 Center Dr., MSC 2520
Bethesda, MD 20892
(301) 496-5717
(301) 402-0120 (fax)
✉ocpostoffice@niaid.nih.gov
http://www.niaid.nih.gov

ARTS

National Arts and Disability Center
300 UCLA Medical Plaza
Ste 3330
Los Angeles, CA 90095-6967
(310) 794-1141
(310) 267-2356 (TTY)
(310) 794-1143 (fax)
✉oraynor@mednet.ucla.edu
http://www.dcp.ucla.edu/nadc/

ASSISTIVE TECHNOLOGY & REHABILITATION EQUIPMENT

ABLEDATA
8401 Colesville Rd Ste 200
Silver Spring, MD 20910
(800) 227-0216 (voice)
(301) 608-8998 (voice)
(301) 608-8912 (TTY)
(301) 608-8958 (fax)
✉abledata@macroint.com
✉kabelknap@aol.com
http://www.abledata.com

CANCER

Cancer Information Service
National Cancer Institute
31 Center Dr., MSC 2580
Building 31, Rm. 10A16
Bethesda, MD
20892-2580
(800) 422-6237 (voice)
(800) 332-8615 (TTY)
(301) 330-7968 (fax)
http://www.nci.nih.gov

DIABETES

National Diabetes Information Clearinghouse
2 Information Way
Bethesda, MD 20892-3570
(301) 654-3327
(301) 907-8906 (fax)
✉ndic@info.niddk.nih.gov
http://www.niddk.nih.gov

DIGESTIVE DISEASES

National Digestive Diseases Information Clearinghouse
2 Information Way
Bethesda, MD 20892-3570
(301) 654-3810
(301) 907-8906 (fax)
✉nddic@info.niddk.nih.gov
http://www.niddk.nih.gov

DISABILITIES

NICHCY (National Information Center for Children & Youth with Disabilities)
PO Box 1492
Washington, DC 20013-1492
(800) 695-0285 (voice/TTY)
(202) 884-8441 (fax)
✉nichcy@aed.org
http://www.nichcy.org

EDUCATION

ERIC CLearinghouse on Disabilities & Gifted Children
Council for Exceptional Children
1920 Association Dr.
Reston, VA 20191-1589
(800) 328-0272 (voice/TTY)
✉ericec@cec.sped.org
http://ericec.org

(NAEYC) National Association for the Education of Young Children
1509 16th St. NW
Washington, DC 20036-1426
(800) 424-2460
(202) 232-8777 (local)
(202) 328-1846 (fax)
✉pubaff@aeyc.org
http://www.naeyc.org

National Clearinghouse on Postsecondary Education for Individuals with Disabilities
HEATH Resource Center
1 Dupont Cir NW, Ste 800
Washington, DC 20036-1193
(800) 544-3284 (voice/TTY)
(800) 939-9320 (voice/TTY)
(202) 833-4760 (fax)
✉heath@ace.nche.edu
http://www.acenet.edu

Office of Special Education & Rehabilitation Services
US Department of Education
330 C St, SW
Switzer Bldg, Rm 3132
Washington, DC 20202-2524
(202) 205-8241 (voice/TTY)
(202) 401-2608 (fax)
http://www.ed.gov/offices/osers

FAMILY HEALTH

Agency for Health Care Policy & Research Publications Clearinghouse
PO Box 8547
Silver Spring, MD 20907-8547
(800) 358-9295
(410) 381-3150
(301) 494-2800 (fax)
http://www.ahcpr.gov

National Center for Education in Maternal & Child Health
2000 15th St N, Ste 701
Arlington, VA 22201-2617
(703) 524-7802
(703) 524-9335 (fax)
✉info@ncemch.org
http://www.ncemch.org

National Center for Health Statistics
6525 Belcrest Rd
Hyattsville, MD 20782-2003
(301) 458-4636
✉nchsquery@nch10a.em.cdc.gov
http://www.cdc.gov/nchswww/nchshome.htm

HSC Health Care System
1025 Connecticut Ave.
Washington, DC 20036
(800) 329-6884
(202) 467-2737
(202) 467-2737 (fax)
✉hscsn@hscsn.org
http://www.hscn.org
1,2,3,4,5,7,9

National Health Information Center (NHIC)
PO Box 1133
Washington, DC 20013-1133
(800) 336-4797
(301) 984-4256 (fax)
✉nhicinfo@health.org
http://nhic-nt.health.org

National Institute of Child Health & Human Development
NICHD Clearinghouse
PO Box 3006
Rockville, MD 20847
(800) 370-2943
(301) 496-7101 (fax)
http://www.nih.gov/nichd/

National Institutes of Health (NIH)
Office of Rare Diseases
31 Center Dr., Rm. 1B03
Bethesda, MD 20892
(301) 402-4336
✉sg18b@nih.gov
http://rarediseases.info.nih.gov/ord

National Maternal & Child Health Clearinghouse
2070 Chain Bridge Rd, Ste 450
Vienna, VA 22182
(703) 821-8955
(703) 821-2098 (fax)
✉nmchc@circsol.com
http://www.circsol.com\

HEARING IMPAIRMENTS

National Information Center on Deafness
Gallaudet University
800 Florida Ave NE
Washington, DC 20002-3695
(202) 651-5051 (voice)
(202) 651-5052 (TTY)
(202) 651-5054 (fax)
✉nicd@gallux.gallaudet.edu
http://www.gallaudet.edu/~nicd

National Institute on Deafness & Other Communication Disorders
Information Clearinghouse
1 Communication Ave
Bethesda, MD 20892-3456
(800) 241-1044 (voice)
(800) 241-1055 (TDD)
(301) 907-8830 (fax)
✉nidcd@nidcd.hih.gov
http://www.nih.gov/nidcd

HEART, LUNG, AND BLOOD DISORDERS

National Heart, Lung, & Blood Institute Information Center
PO Box 30105
Bethesda, MD 20824-0105
(800) 573-9355
(301) 251-1222
(301) 251-1223 (fax)
✉nhlbiic@dgsys.com
http://www.nhlbi.nih.gov/nhlbi/

HOUSING

Housing & Urban Development User
PO Box 6091
Rockville, MD 20849
(800) 245-2691 (voice)
(301) 251-5154 (voice)
(800) 483-2209 (TTY)
(301) 519-5767 (fax)
✉huduser@aspensys.com
http://www.huduser.org

KIDNEY AND UROLOGIC DISEASES

National Kidney & Urologic Diseases
Information Clearinghouse
3 Information Way
Bethesda, MD 20892-3580
(301) 654-4415
✉nkudic@info.niddk.nih.gov
http://www.niddk.nih.gov

MENTAL HEALTH

(KEN) National Mental Health Knowledge Exchange Network
11426-28 Rockville Pike, Ste 405
Rockville, MD 20852
(800) 789-2647
(301) 984-8796 (fax)
http://www.mentalhealth.org

Research and Training Center on Family Support and Children's Mental Health
Regional Research Institute
Portland State University
PO Box 751
Portland, OR 97207
(503) 725-4040
(503) 725-4180 (fax)
http://www.rtc.pdx.edu

MUSCULOSKELETAL & SKIN DISEASES

National Arthritis & Musculoskeletal & Skin Diseases Information Clearinghouse
1 AMS Cir
Bethesda, MD 20892-3675
(301) 495-4484 (voice)
(301) 565-2966 (TTY)
(301) 587-4352 (fax)
http://www.nih.gov/niams

NEUROLOGICAL DISORDERS

National Institute of Neurological Disorders & Stroke
PO Box 5801
Bethesda, MD 20824
(800) 352-9424
(301) 496-5751
(301) 402-2186 (fax)
http://www.ninds.nih.gov

Federal & Federally Funded Information Resources

ORAL HEALTH

National Oral Health Information Clearinghouse
1 NOHIC Way
Bethesda, MD 20892-3500
(301) 402-7364 (voice)
(301) 656-7581 (TTY)
(301) 907-8830 (fax)
✉nidr@aerie.com
http://www.aerie.com/nohicweb

PRIMARY CARE

Circle Solution
2070 Chain Bridge Rd, Ste 450
Vienna, VA 22182
(703) 821-8955, ext 248 (voice)
(703) 566-4831 (TTY/TDD)
(703) 821-2098 (fax)
✉info@circsol.com
http://www.circsol.com

REHABILITATION

NARIC (National Rehabilitation Information Center)
8455 Colesville Rd, Ste 935
Silver Spring, MD 20910-3319
(800) 346-2742 (voice)
(301) 495-5626 (voice/TTY)
(301) 587-1967 (fax)
http://www.naric.com.naric

VISUAL IMPAIRMENTS

National Eye Institute
Bldg 31, Rm 6A32
31 Center Dr, MSC 2510
Bethesda, MD 20892-2510
(301) 496-5248
(301) 402-1065 (fax)
✉2020@nei.nih.gov
http://www.nei.nih.gov

OTHER FEDERAL RESOURCES

These federal resources can provide information on programs, services, and related laws and regulations.

Administration on Developmental Disabilities US Department of Health & Human Services
Washington, DC 20201
(202) 690-6590 (voice)
(202) 690-6415 (TTY)
(202) 690-6904 (fax)
http://www.acf.dhs.gov/programs/ada

Department of the Interior National Park Service
1849 C St. NW
Washington, DC 20240
(202) 208-4747
(202) 219-0910 (fax)
http://www.nps.gov

Division of Birth Defects & Developmental Disabilities
National Center for Environmental Health Centers for Disease Control & Prevention
4770 Buford Hwy NE
Mailstop F-34
Atlanta, GA 30341
(770) 488-7150
(770)488-7156 (fax)
http://www.cdc.gov

Indian Health Servcice
Mental Health/Social Service Programs Branch
5300 Homestead Rd NE
Albuquerque, NM 87110
(505) 248-4245
(505) 248-4257 (fax)

Job Accommodation Network
West Virginia University
#1, 918 Chestnut Ridge Rd
Morgantown, WV 26506-6080
(800) 232-9675 (voice/TTY)
(800) 526-7234 (voice/TTY)
(800) 526-2262 (voice/TTY, Canada)
(304) 293-5407 (fax)
✉jan@jan.wvu.edu
janweb.icdi.wvu.edu

National Council on Disability
1331 F St NW, Ste 1050
Washington, DC 20004-1107
(202) 272-2004 (voice)
(202) 272-2074 (TTY)
(202) 270-2022 (fax)
http://www.ncd.gov

National Library Service for the Blind & Physically Handicapped
Library of Congress Reference Section
1291 Taylor St NW
Washington, DC 20542
(202) 707-5100 (voice)
(202) 707-0744 (TTY)
(202) 7070-0712 (fax)
✉nis@loc.gov
http://www.loc.gov/nls

Office for Fair Housing & Equal Opportunity Department of Housing & Urban Development
Washington, DC 20002
(202) 275-0848 (voice)
(202) 275-0772 (TTY)
(202) 275-2987 (fax)

Office of Special Education & Rehabilitative Services (OSERS)
US Department of Education
Switzer Bldg
330 C St SW
Washington, DC 20202-2524
(202) 205-8723 (voice)
(202) 205-8241 (TTY)
(202) 401-2608 (fax)

President's Committee on Employment of People with Disabilities
1331 F St NW, 3rd Flr
Washington, DC 20004
(202) 376-6200 (voice)
(202) 376-6205 (TTY)
(202) 376-6219 (fax)
http://www.pcepd.gov

President's Committee on Mental Retardation
Hubert H Humphrey Bldg, Rm 352G
200 Independence Ave SW
Washington, DC 20201
(202) 619-0634
(202) 205-9519 (fax)

Senate Subcommittee on Disability Policy
113 Hart Senate Office Bldg
Washington, DC 20510
(202) 224-6265 (voice)
(202) 224-3457 (TTY)
(202) 228-2923 (fax)
✉tom_harkin@harkin.senate.gov

Social Security Administration
6401 Security Blvd
Baltimore, MD 21235
(800) 772-1213 (voice hotline)
(800) 325-0778 (TTY hotline)
http://www.ssa.gov

CANADIAN RESOURCES

The following Canadian resources can provide information on disability-related topics and referrals to local resources. In addition to the federally-funded Canadian Clearinghouse on Disability Issues, most provincial governments fund similar information resources for their citizens. Unless otherwise indicated, all telephone numbers are for voice only.

NATIONAL CLEARINGHOUSE

Office for Disability Issues Human Resource Development Canada
25 Eddy St, Ste 100
Hull PQ K1A 0M5
(800) 665-9017 (voice, Can only)
(800) 561-9706 (TTY, Can only)
(819) 994-7514 (voice)
(819) 953-4797 (fax)
✉odi@indie.ca
http://www.indie.ca/odi/

BRITISH COLUMBIA

Office for Disability Issues
PO Box 9567
STNPROVGOT, Victoria BC V8W 9K1
(800) 663-7867 (voice, BC only)
(250) 387-3813 (voice)
(250) 387-3555 (TTY)
(250) 387-3114 (fax)
✉acorbett@hre.gov.nf.ca
http://www.disability.gov.bc.ca/

MANITOBA

Manitoba League of Persons With Disabilities 200
294 Portage Ave
Winnepeg, MB R3C 0B9
(204) 943-6099 (voice/TTY)
(204) 943-3146 (fax)
✉mlpd@mb.sympatico.ca
http://www.mlpd.mb.ca

NEWFOUNDLAND

Department of Health and Community Services
Main Floor, Confederation Bldg.
PO Box 8700
St John's, NF A1B 4J6
(709) 729-2436
(709) 729-6382 (fax)
✉peicod@pei.sympatico.ca

NOVA SCOTIA

The Novia Scotia Disabled Persons Commission
203, 2695 Dutch Village Rd
Halifax, NS B3L 4T9
(800) 565-8280 (voice, NS only)
(902) 424-8280 (voice)
(902) 424-2667 (TTY)
(902) 424-0592 (fax)
✉dpcomm@gov.ns.ca

PRINCE EDWARD ISLAND

PEI Council of the Disabled
PO Box 2128
Charlottetown EI, C1A 7N7
(902) 892-9149 (voice/TTY)
(902) 566-1919 (fax)
✉peicod@pei.sympatico.ca

QUEBEC

Office des Personnes Handicapees du Quebec
309 Rue Brock
Drummondville, PQ J2B 1C5
(800) 567-1477(voice, PQ only)
(800) 567-1465 (TTY, PQ only)
(819) 475-8585 (voice)
(819) 475-8753 (fax)
✉info@ophq.gouv.qc.ca
http://www.ophq.gouv.qc.ca

NOTES:

National Information & Advocacy Resources

These national organizations are information and advocacy resources for families and professionals. This directory starts with a listing of organizations providing general information and advocacy, followed by organizations focusing on more specific areas of concern to families of children and young adults who have disabilities.

Numbers following each listing correspond to items listed in the **Key to Services**, which describes services provided by individual organizations.

When available, World Wide Web sites and e-mail addresses have been included. Web sites are listed with the standard **http://** before each. E-mail addresses are indicated by the symbol, ✉. (Unless otherwise indicated, all telephone numbers are for voice only.)

ACCESSIBLE PLAYGROUNDS

Boundless Playgrounds Hasbro National Resource Center
968 Farmington Ave.
West Hartford, CT 06107
(877) 268-6353
(860) 586-8990
(860) 236-1749 (fax)
http://www.boundlessplaygrounds.org
1,2,3,4,7,9; helping communities develop accessible playgrounds

ADOPTION

A Kids Exchange
c/o Janet Marchese
56 Midchester Ave.
White Plains, NY 10606
(914) 428-1236
3

AASK: Adopt A Special Kid
287 17th St., Ste. 207
Oakland, CA 94612-4123
(510) 451-1748
(510) 451-2023 (fax)
http://www.adoptaspecialkid.org
✉andrea@adoptaspecialkid.org
1,2,3,5

Adoptive Families of America
2309 Como Ave.
St. Paul, MN 55108
(800) 372-3300
(651) 645-9955
(651) 645-0055 (fax)
http://www.adoptivefam.org
1,2,3,5,6,8

Friends Health Connection
PO Box 114
New Brunswick, NJ 08903
(800) 483-7436
(732) 249-9897 (fax)
http://www.48friends.com
3

Jewish Children's Adoption Network
PO Box 16544
Denver, CO 80216-0544
(303) 573-8113
(303) 893-1447 (fax)
http://www.users.uswest.net/~jcan
✉jcan@uswest.net
1,2,3,4,5,6,9; Hebrew/Yiddish materials

National Adoption Center
1500 Walnut St., Ste. 701
Philadelphia, PA 19102
(800) 862-3678
(215) 735-9988
(215) 735-9410 (fax)
http://www.adopt.org
✉nac@adopt.org
1,2,3,5

Spaulding for Children
16250 Northland Dr., Ste. 120
Southfield, MI 48075
(248) 443-7080
(248) 443-7099 (fax)
http://www.spaulding.org
1,2,3,6

ARCHITECTURAL ACCESSIBILITY

Center for Universal Design
North Carolina State University
School of Design
Raleigh, NC 27695-8613
(800) 647-6777 (Voice/TTY, US & Canada)
(919) 515-3082 (Voice/TTY)
(919) 515-3023 (fax)
http://www.design.ncsu.edu/cud
✉cand@ncsu.edu
1,2

ARTS

National Arts and Disability Center
300 UCLA Medical Plaza, Ste. 3330
Los Angeles, CA 90095-6967
(310) 825-5054
(310) 794-1143 (fax)
http://nadc.ucla.edu
✉bstoffmacher@mednet.ucla.edu
2,4,5

ASSISTIVE TECHNOLOGY

Arkenstone, Inc.
Nasa Ames Moffett Complex,
Bldg. 23, PO Box 215
Moffett Field, CA 94035-0215
(650) 603-8880
(650) 603-8887 (fax)
http://www.arkenstone.org
✉info@arkenstone.org
2; software for visually impaired and learning disabilities

Macomb Project
27 Horrabin Hall
Western Illinois University
Macomb, IL 61455
(309) 298-1634
(309) 298-2305 (fax)
http://www.mprojects.wiu.edu
✉L_Robinson@wiu.edu
1,2

New Hampshire Assistive Technology Center
5 Right Way Path
Laconia, NH 03246-0109
(603) 528-3060
(603) 524-0702 (fax)
✉nhatech@cyberportal.net
1,2,4

Lekotek's CompuPlay Programs
The National Lekotek Center
2100 Ridge Ave.
Evanston, IL 60201
(800) 366-7529 (Toy Resource Helpline)
(800) 573-4446 (TTY)
(847) 328-5514 (fax)
http://www.lekotek.com
✉lekotek@lekotek.com

BREASTFEEDING

LaLeche League International
1400 N. Meacham Rd.
Schaumberg, IL 60173
(800) LALECHE
(847) 519-7730
(847) 519-0035 (fax)
http://www.lalecheleague.org
✉PRDepartmant@llli.org

CHILD CARE

Child Care Plus+
634 Eddy, Rural Institute on Disabilities
University of Montana
Missoula, MT 59812
(800) 235-4122
(406) 243-5467 (v/TTY)
(406) 243-4730 (fax)
http://ruralinstitute.umt.edu childcareplus
✉sarahmg@selway.umt.edu
1,2,; Networking

The National Center for Child Care Inclusion
PO Box 775
Sydney, NS CAN B1P 6G9
(800) 840-5465 (Canada only)
(902) 562-1662
(902) 539-9117 (fax)
http://www.cbnet.ns.ca/~specialink
✉speclink@atcon.com
1,2,3,4,5,6,7,9

DEVELOPMENTAL DISABILITIES

Center for Literacy and Disability Studies
PO Box 3888
Duke University Medical Center
Durham, NC 27710
(919) 684-3740
(919) 681-5738 (fax)
http://www.surgery.mc.duke.edu/hearing/clds/
✉literacy@acpub.duke.edu
2,6

Developmental Delay Registry
6701 Fairfax Rd.
Chevy Chase, MD 20815
(301) 652-2263
(301) 229-5005 (fax)
http://www.devdelay.org
✉plemer@compuserve.com
1,2,3,5,9

EARLY DETECTION, INTERVENTION, AND INCLUSION

Pathways Awareness Foundation
123 N. Wacker Dr.
Chicago, IL 60606
(800) 364-1337
(847) 729-1116
http://www.pathwaysawareness.org
✉friends@pathwaysawareness.org
1,2,5,6

EDUCATION

National Coalition of Title I/Chapter I Parents
1541 14th St. NW
Washington, DC 20005
(202) 547-9286
(202) 544-2813 (fax)
1,2,3,4,5,6,7,8,9; scholarship program

EMPLOYMENT

Electronic Industries Foundation
2500 Wilson Blvd., Ste. 210
Arlington, VA 22201
(703) 907-7400
(703) 907-7422 (TTY)
(703) 907-7421 (fax)
http://www.eia.org/eif
scholarship program

Job Opportunities for the Blind National Federation of the Blind
1800 Johnson St
Baltimore, MD 21230
(410) 659-9314
(410) 685-5653 (fax)
http://www.nfb.org
✉nfb@iamdigex.net
2,4,6,9

Just One Break, Inc.
120 Wall St.
New York, NY 10005
(212) 785-7300
(212) 785-4513 (fax)
http://www.justonebreak.com
✉justonebreak@interactive.net
1,2,5,6; braille informational materials

Mainstream
6930 Carroll Ave., Ste. 240
Takoma Park, MD 20912
(301) 891-8777 (voice/TTY)
(301) 891-8778 (fax)
http://www.mainstreaminc.org
✉info@mainstreaminc.org
1,2,4,5

National Industries for the Severely Handicapped
2235 Cedar Ln.
Vienna, VA 22182
(703) 560-6800
(703) 849-8916 (fax)
http://www.nish.org
1,2,5,6,7

Parents Alliance Employment Project
Illinois Employment
& Training Center
837 S. Westmore Rd.
Lombard, IL 60148
(630) 495-4345 Ext 211
(630) 495-6055 (TTY)
(630) 495-0387 (fax)
✉tweekley@iatc-dupagw.com
1,2,3,4

FOSTER CARE PLACEMENT

Handle with Care
PO Box 1569
Wimberly, TX 78676
(888) 590-5049
(512) 842-1163
(512) 847-6257 (fax)
http://www.handle-care.org
✉inio@handle-care.org
1,2,3,4,8 ; Foster care placement for children who are medically fragile and/or chronically ill.

GENERAL

Advocates Across America
PO Box 754
Chandler, AZ 85244-0754
(480) 917-0955
(480) 814-9404 (fax)
http://www.axa.org
✉support@axa.org
1,2,3,5,6

The American Association of Retired Persons (AARP)
601 E. St., NW
Washington, DC 20049
(800) 424-3410
(202) 434-6561

American Association of University Affiliated Programs for Persons with Developmental Disabilities
8630 Fenton St, Ste 4120
Silver Spring, MD 20910
(301) 588-8252 (voice)
(301) 588-3319 (TTY)
(301) 588-2842 (fax)
http://www.aaup.org
✉AAUAPJONES@aol.com
2,4,7

The Arc of the U.S.
500 E. Border, Ste. 300
Arlington, TX 76010
(800) 433-5255
(817) 261-6003
(817) 277-3491 (fax)
http://www.TheArc.org
✉thearc@metronet.com
1,4

Association of Birth Defect Children
930 Woodcock Rd., Ste. 225
Orlando, FL 32803
(800) 313-2232 (voice, 24-hour registry line)
(407) 245-7035
(407) 895-0824 (fax)
http://www.birthdefects,org
✉abdc@birthdefects.org
1,2,3,4,7,9

Children's Defense Fund
25 E Street NW
Washington, DC 20001
(800) 233-1200
(202) 628-8787
(202) 662-3510 (fax)
http://www.childrensdefense.org
✉cdfinfo@childrensdefense.org
1,2,4,6,8

Council for Exceptional Children
1920 Association Dr.
Reston, VA, 20191-1589
(800) 232-7733
((703) 620-3660
(703) 264-9494 (fax)
http://www.cec.sped.org
1,2,4,6,8

KEY TO SERVICES

1 Periodical/newsletter
2 Informational materials
3 Networking/matching
4 Referrals to local resources
5 Local chapters
6 National conferences
7 National advocacy efforts
8 Fund research
9 Maintain research registry

National Information & Advocacy Resources

Easter Seals National Office
230 W. Monroe, Ste. 1800
Chicago, IL 60606-4802
(800) 221-6827 (voice)
(312) 726-6200 (voice)
(312) 726-4258 (TTY)
(312) 726-1494 (fax)
http://www.seals.com
✉nessinfo@seals
2,4,5

Family Voices
PO Box 769
Algodones, NM 87001
(888) 835-5669
(505) 867-2368
(505) 867-6517 (fax)
http://www.familyvoices.org
✉kidshealth@familyvoices.org
1,2,5,6

Institute for Health & Disability
Division of General Pediatrics
& Adolescent Health
University of Minnesota
Box 721, 420 Delaware St SE
Minneapolis, MN 55455
(612) 624-3939 (Voice/TTY)
(612) 626-2134 (fax)
http://www.peds.umn.edu/Centers/
✉instihd@tc.umn.edu
1,2; limited Spanish materials

March of Dimes Birth Defects Foundation
1275 Mamaroneck Ave
White Plains, NY 10605
(888) 663-4637
(914) 997-4763 (fax)
http://www.modimes.org
resourcecenter@modimes.org
2,5,7,8

National Family Caregivers Association
10605 Concord St., Ste. 50
Kensington, MD 20895-2504
(301) 942-6430
(301) 942-2302 (fax)
http://www.nfcacares.org
info@nfcacares.org
1,2,3

National Father's Network
The Kindering Center
16120 NE 8th St.
Bellevue, WA 98008-3937
(425) 747-4004 ext. 218
(206) 284-2859
(425) 747-1069 (fax)
(206) 284-9664 (fax)
http://www.fathersnetwork.org
✉jmay@fathersnetwork.org

National Organization on Disability
910 16th St. NW, Ste. 600
Washington, DC 20006
(202) 293-5960
(202) 293-5968 (TTY)
(202) 293-7999 (fax)
http://www.nod.org
✉ability@nod.org
2,4,5,7

National Vaccine Information Center
512 W. Maple Ave., #206
Vienna, VA 22180
(703) 938-0342
(703) 938-5768 (fax)
http://www.909shot.com
✉KWilliams9@mindspring.com
1,2,3,4,5,6,7,9

NICHCY: National Information Center for Children and Youth with Disabilities
PO Box 1492
Washington, DC 20013
(800) 695-0285 (voice/TTY)
(202) 884-8200 (voice/TTY)
(202) 884-8441 (fax)
http://www.nichy.org
✉nichy@aed.org
2,4; many publications available in Spanish

NPA: National Perinatal Association
3500 E. Fletcher Ave., Ste. 209
Tampa, FL 33613-4712
(813) 971-1008
(813) 971-9306 (fax)
http://www.nationalperinatal.org
✉npaonline@aol.com
1,2,4,5,6,8

NPND: National Parent Network on Disabilities
1130 17th St., NW, Ste. 400
Washington, DC 20005
(202) 463-2299
(202) 463-9403 (fax)
http://www.npnd.org
✉npnd@c.s.net
1,2,4,5,6,7

RESNA
1700 N. Moore St., Ste. 1540
Arlington, VA 22209
(703) 524-6686
(703) 524-6630 (fax)

Rural Institute on Disabilities Montana University Affiliates
52 Corbin Hall
University of Montana
Missoula, MT 59812
(800) 732-0323 (voice/TTY)
(406) 243-5467 (voice/TTY)
(406) 243-4730 (fax)
http://www.ruralinstitute.umt.edu
✉muarid@selway.umt.edu
1,2,5,6

SNAP: Special Needs Advocate for Parents
1801 Avenue of the Stars #401
Century City, CA 90067
(888) 310-9889
(310) 201-9614
(310) 201-9889 (fax)
http://www.snapinfo.org
✉info@snapinfo.org
1,2,4,5,6,8

STOMP: Specialized Training of Military Parents
c/o Washington PAVE
6316 S. 12th St.
Tacoma, WA 98465
(800) 5-PARENT (v/TTY)
(253) 565-2266 (v/TTY)
(253) 566-8052 (fax)
http://www.washingtonpave.org
✉wapave9@washingtonpave.com

The Roeher Institute
Kinsmen Bldg, York University
4700 Keele St
North York, ON CAN M3J IP3
(416) 661-9611
(416) 661-5701 (fax)
✉info@roeher.ca
1,2,5,6,7

World Institute on Disability
510 16th St., Ste. 100
Oakland, CA 94612-1502
(510) 763-4100
(510) 208-9493 (TTY)
(510) 763-4109 (fax)
http://www.wid.org
✉wid@wid.org
2,4

GENETICS

Alliance of Genetic Support Groups
4301 Connecticut Ave. NW, Ste. 404
Washgton, DC 20008-2304
(800) 336-GENE
(202) 966-5557
(202) 966-8553 (fax)
http://www.geneticalliance.org
✉info@geneticalliance.org

Hereditary Disease Foundation
1427 7th St., Ste. 2
Santa Monica, CA 90401
(310) 458-4183
(310) 458-3937 (fax)
✉cures@hdfoundation.org
1,2

HEALTHCARE

Association for the Care of Children's Health
19 Mantua Rd
Mt. Royal, NJ 08061
(800) 808-ACCH
(609) 423-3420 (fax)
http://www.acch.org
✉acchq@talley.com
1,2,4,8

Children's Hospice International
2202 Mount Vernon Ave., Ste. 3C
Alexandria, VA 22301
(800) 242-4453
(703) 684-0330
(703) 684-0226 (fax)
http://www.chionline.org
✉chiorg@aol.com
1,2,3,4,5,6,7

National Health Council
1730 M St. NW, Ste. 500
Washington, DC 20036-4505
(202) 785-3910
(202) 785-5923 (fax)
http://www.healthanswers.com
✉info@nhcouncil.org
1,2,4,6,7

St. Mary's Healthcare System for Children
c/o Rhonda Broden
29-01 216th St
Bayside, NY 11360
(718) 281-8750
(718) 281-8773 (fax)
http://www.stmaryskids.org
5,6,7

The Institute for Health & Disability
University of Minnesota
Box 721 UMHC
420 Delaware St. SE D-118
Minneapolis, MN 55455
(612) 624-3939 (v/TTY)
(612) 626-2134 (fax)
http://www.peds.umn.edu/centers
✉instihd@tc.umn.edu
1,2,3,4,5,6

INDEPENDENT LIVING

Disabled and Alone/Life Services for the Handicapped, Inc.
352 Park Ave. S., Ste. 703
New York, NY 10010-1709
(212) 532-6740 (v/fax)
(800) 995-0066
http://www.hsca.org/disabledandalone
✉disabledandalone@juno.com

Independent Living Research Utilization Program
2323 S Shepherd, Ste 1000
Houston, TX 77019
(713) 520-0232 (voice)
(713) 520-5136 (TTY)
(713) 520-5785 (fax)
http://www.ilru.org
✉ilru@ilru.org
1,2,3,6,7

INFORMATION AND REFERRALS

National Christian Resource Center
Bethesda Lutheran Homes
700 Hoffman Dr.
Watertown, WI 53094
(800) 369-4636 (INFO)
2,4; Referrals to local services, advocacy and support groups, and religious education programs; Lists or religious materials.

SNAP: Special Needs Advocate for Parents
1801 Avenue of the Stars #401
Century City, CA 90067
(888) 310-9889
(310) 201-9614
(310) 201-9889 (fax)
http://www.snapinfo.org
✉info@snapinfo.org
1,2,4,5,6,8

LEGAL ASSISTANCE

DREDF: Disability Rights Education and Defense Fund
Main Office:
2212 Sixth St
Berkeley, CA 94710
(800) 466-4232 (Voice/TTY)
(510) 644-2555 (Voice/TTY)
(510) 841-8645 (fax)
http://www.dredf.org
✉dredf@dredf.org
1,2,3

National Association of Protection and Advocacy Systems
900 2nd St. NE, Ste. 211
Washington, DC 20002
(202) 408-9514
(202) 408-9521 (TTY)
(202) 408-9520 (fax)
http://www.protectionandadvocacy.com
✉NAPAS@earthlink.net
1,2,4,5,6

Pike Institute on Law and Disability
Boston University School of Law
765 Commonwealth Ave
Boston, MA 02115-1620
(617) 353-2904 (Voice/TTY)
(617) 353-2906 (fax)
web.bu.edu/pike
✉pikeinst@bu.edu
2,4,5

MEDICAL TRAVEL/TRANSPORTATION

National Patient Travel Center
4620 Haygood Rd., Ste.1
Virginia Beach, VA 23455
(800) 296-1217 (Patient #)
(757) 318-9174 (Administrative #)
(757) 318-9107 (fax)
http://www.PatientTravel.org
✉mercymedical@erols.com

PREMATURITY

The Alexis Foundation for Premature Infants and Children
PO Box 1126
Birmingham, MI 48012-1126
(248) 543-4169 (Phone/fax)
✉thealexisfoundation@prodigy.net
1,2,3,4; Also provides preemie clothing.

RARE DISORDERS

Canadian Organization for Rare Disorders
PO Box 814
Coaldale, AB CAN T1M 1M7
(403) 345-4544
(403) 345-3948 (fax)
http://www.bully.com/~cord
✉cord@bully.com
3,5,6

MUMS: National Parent to Parent Network
c/o Julie Gordon
150 Custer Ct.
Green Bay, WI 54301-1243
(920) 336-5333
(920) 339-0995 (fax)
http://www.netnet.net/mums/
✉mums@netnet.net
1,2,3,5,8,9

NORD: National Organization for Rare Disorders, Inc.
100 Rt. 37
PO Box 8923
New Fairfield, CT 06812
(800) 999-6673 (voice meesage)
(203) 746-6518 (voice)
(203) 746-6927 (TTY)
(203) 746-6481 (fax)
http://www.rarediseases.org
✉orphan@raredisease.org
1,2,3,4,5,6,7,8,9

REHABILITATION

Easter Seal/March of Dimes National Council
90 Eglinton Ave E, Ste. 511 Toronto,
ON CAN M4P 2Y3
(416) 932-8382 (voice)
(416) 932-8151 (TTY)
(416) 932-9844 (fax)
http://www.esmaodnc.org
✉national.council@smodnc.org
1,2,4,5,6,8

RESPITE CARE

National Respite Locator Service
800 Eastowne Dr., Ste 105
Chapel Hill, NC 27514
(800) 773-5433
(919) 490-4905 (fax)
http://www.chtop.com/locator.htm
database with respite services

KEY TO SERVICES

1	Periodical/newsletter
2	Informational materials
3	Networking/matching with other families
4	National conferences
5	Referrals to local resources
6	National advocacy efforts
7	Fund research
8	Local chapters
9	Maintain research registry

SELF-HELP

American Self-Help Clearinghouse
Northwest Covenant Medical Center
25 Pocono Rd.
Denville, NJ 07834
(201) 625-9565 (voice)
(201) 625-9053 (TTY)
(201) 625-8848 (fax)
http://www.cmhc.com/selfhelp
✉ashc@bc.cybernet.net
2,4

NATIONAL SELF-HELP CLEARINGHOUSE
CUNY Grad School, University Ctr.
25 W. 43rd St., Rm 620
New York, NY 10036
(212) 354-8525
(212) 642-1956 (fax)
http://www.selfhelpweb.org
1,2,5

SEXUALITY

Sexuality Information and Education Council of the U.S.
130 W 42nd St., Ste. 350
New York, NY 10036-7802
(212) 819-9770
(212) 819-9776 (fax)
http://www.siecus.org
✉siecus@siecus.org
1,2,6

SIBLING SUPPORT

Sibling Information Network
The A.J. Pappanikou Center on Special Education and Rehabilitation
249 Glenbrook Rd U-64
Storrs, CT 06269-2064
(860) 486-4985
(860) 486-5037 (fax)
✉speadm01@uconnvm.uconn.edu
1

Sibling Support Project
Children's Hospital and Regional Medical Center
PO Box 5371 CL-09
Seattle, WA 98105-0371
(206) 527-5711
(206) 527-5705 (fax)
http://www.chmc.org/departmt/sibsupp
✉dmeyer@chmc.org
2,9

SUICIDE PREVENTION

American Foundation for Suicide Prevention
120 Wall St., 22 Fl.
New York, NY 10005
(212) 365-3500
(212) 363-6237 (fax)
http://afsp.org
✉inquiry@afsp.org
1,2,4,5,6,7,8

TOY LENDING AND ADAPTATIONS

The National Lekotek Center
2100 Ridge Ave.
Evanston, IL 60201
(800) 366-7529 (Toy Resource Helpline)
(800) 573-4446 (TTY)
(847) 328-5514 (fax)
http://www.lekotek.com
✉lekotek@lekotek.com
1,2,4,5,6,8

TRAINING PROGRAMS

Project DOCC-
Delivery of Chronic Care
One South Rd.
Oyster Bay, NY 11771-1905
(516) 365-0959
(516) 365-4339 (fax)
http://www.projdocc.com
✉projdocc@aol.com
1,2,6

TRAVEL

Mobility International USA
PO Box 10767
Eugene, OR 97440
(541) 343-1284 (v/TDD)
(541) 343-6812 (fax)
http://www.miusa.org
✉info@miusa.org
1,2,4

WISH ORGANIZATIONS

Children's Hopes and Dreams
Wish Fulfillment Foundation
280 Rt. 46
Dover, NJ 07801
(973) 361-7366
(973) 361-6627 (fax)
http://www.childrenscharities.org/childrens_wishes.html
✉chdfdover@juno.com
1,2,3,5,6

Children's Wish Foundation International
8615 Roswell Rd
Atlanta, GA 30350
(800) 323-9474
(770) 393-9474
(770) 393-0683 (fax)
http://www.childrenswish.org
✉childrenswish@minspring.com
1,2,4

Grant-A-Wish Foundation
c/o Brian Morrison
PO Box 21211
Baltimore, MD 21228
(800) 933-5470
(410) 242-1549
(410) 242-8818 (fax)
http://www.grant-a-wish.org
✉grant-a-wish@worldnet.att.net
1,2

Make-A-Wish Foundation of America
100 W. Clarendon, Ste. 2200
Phoenix, AZ 85013-3518 (800) 722-9474
(602) 279-9474
(602) 279-0855 (fax)
http://www.wish.org
✉info@wish.org
2,4,5

Sunshine Foundation
2001 Bridge St
Philadelphia, PA 19124
(800) 767-1976
(215) 535-1413
(215) 535-8397 (fax)
2

The Children's Wish Foundation of Canada
95 Bayly St., Ste. 404
Ajax, ON CAN L1S 7K8
(800) 267-9474
(905) 426-5656
(905) 426-4111 (fax)
✉wishes.national@sympatico.ca
1,2,4,5

The Dream Factory
1218 S. Third St.
Louisvile, KY 40203
(800) 456-7556
(502) 637-8700
(502) 637-8744 (fax)
http://www.dreamfactoryinc.org
✉dfhqtrs@aol.com
2,4

EXCEPTIONAL PARENT
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WE MOVE international Guide to Movement Disorder Organizations and Foundations

WE MOVE is a not-for-profit organization dedicated to providing information, support, and educational materials to people with movement disorders, their advocates, and healthcare professionals. Our goal is to promote awareness of movement disorders for the purpose of early diagnosis, appropriate treatment, and patient support.

This guide provides a comprehensive listing of national, regional, and international support organizations and foundations committed to improving the quality of life for people with movement disorders. It also appears on our Web site. Most of these organizations have established support services with local chapter affiliates for individuals with specific movement disorders and their families. Many provide referrals, publish educational materials, host Web sites, raise funds, and provide grant money for scientific research. These services are identified at the end of each listing and a **key to services** appears on every other page. We are grateful for the contributions from these organizations and we encourage healthcare professionals to actively support them on all levels.

WE MOVE can assist those who wish to establish new organizations where no national group exists. As we learn of other groups and more people seeking ways to help others with movement disorders, this listing continues to expand.

To learn more, contact: WE MOVE, 204 W. 84th St., New York, NY, 10024, USA; telephone: (800) 437-6682; (212) 241-8567 (outside US); or (212) 875-8389; e-mail: wemove@wemove.org; Web site: www.wemove.org.

USING THIS DIRECTORY

When available, World Wide Web sites and e-mail addresses have been included. Web sites are listed with the standard **http://** before each. E-mail addresses are indicated by the symbol, ✉. (Unless otherwise indicated, all telephone numbers are for voice only.)

ATAXIA

AUSTRALIA

Friedreich's Ataxia Association of New South Wales
Chisholm Street 31a
Turramurra, 2074, Australia
(61) 2 94408233

Spino Cerebellar Ataxia Resources & Support (SCARS)
7 Robilliard Street
Mays Hill 2145, Australia
✉michelle@bmu.net.au

Belgium
Association Belge de l'Ataxie de Friedreich et des autres
Rue Longe 68
Bouffioulx B-6200, Belgium
(32) 71 594248 (phone/fax)

Fondation de l'Ataxie Cerebelleuse (FAC)
Avenue Messidor, 332 boite 4
B-1180 Bruxelles, Belgium

V.Z.W. Vlaamse Liga voor Ataxie van Friedreich en andere erfelijke ataxieïn
European Federation of Hereditary Ataxias (Euro-Ataxia)
Kleine Kuipersstraat 27
Brugge B-8000, Belgium
32 50 333043
✉jefandr@innet.be
http://www.club.innet.be/~pub00028/vlaf.htm

CANADA

Canadian Assoc. of Friedrich's Ataxia
5620 C.A. Jobin Street
Montreal, Quebec H1P 1H8, Canada
Contact: Claude St-John
(514) 321-8684
(514) 321-9257 (fax)
n, br, sg, rs, th, fe, rg

EUROPEAN

European Federation of Hereditary Ataxias
Haagwindelaan 19
Overijse B-3090, Belgium
Contact: Dagmar Kroebel
(32) 2 657-1510
(32) 2 657-6176 (fax)
✉dore@frg.eur.nl
http://www.vsn.nl/euroatax/index.htm
n, br, sg

FINLAND

Rare Neurological Disabilities Group
Suomen MS-Liitto - Finlands MS-F'rbund
European Federation of Hereditary Ataxias (Euro-Ataxia)
Seppalantie 90
Masku FIN-21251, Finland
358 2 4392111
358 2 4392133 (fax)
http://www.ms-liitto.fi

FRANCE

Association Strumpell-Lorrain
European Federation of Hereditary Ataxias (Euro-Ataxia)
9 bis, rue Fabre
Besancon F-25000, France
33 3 81502391 (fax)
✉asl.spastic@wanadoo.fr
n, v, br, sg

GERMANY

Deutsche Heredo-Ataxie Gesellschaft
European Federation of Hereditary Ataxias (Euro-Ataxia)
Bundesverband e.v.
Haussmannstrasse 6
Stuttgart D-70188, Germany
49 711 2155114
49 711 2155214 (fax)
http://ourworld.compuserve.com/homepages/DHAG

IRELAND

Friedrich's Ataxia Society of Ireland
Mart Lane, Foxrock
Dublin 18, Ireland
Contact: Clare Creedon, San Martin
(353) 1289-47-88
http://homepages.iol.ie/~johnpool/society.htm

ITALY

Associazione Italiana per la lotta alle Sindromi Atassiche
European Federation of Hereditary Ataxias (Euro-Ataxia)
Via Cattaneo 22
Magenta (MI) I-20013, Italy
39 2 9792271
✉ aisa@iol.it
http://www4.iol.it/associazioni/aisa

SPAIN

Asociacion Madrilena de Ataxias Hereditarias
European Federation of Hereditary Ataxias (Euro-Ataxia)
C/. Galileo 69, 1
Madrid E-28015, Spain
34 1 4482169

SWEDEN

Ataxia Group - Neurologiskt Handikappades Riksf'rbund
European Federation of Hereditary Ataxias (Euro-Ataxia)
Box 3284
Stockholm S-10365, Sweden
46 8 6777010
46 8 241315 (fax)

SWITZERLAND

Schweizerische Gesellschaft fur Muskelkrankheiten
European Federation of Hereditary Ataxias (Euro-Ataxia)
Rutihofstrasse 21
Zurich 8049 CH-8046, Switzerland
Contact: c/o Daniela Iser
41 1 3402323
41 1 3402324 (fax)
✉diser@access.ch
n, v, br, ep, sg, rs, fe, rg

THE NETHERLANDS

ADCA-Vereniging Nederland
European Federation of Hereditary Ataxias (Euro-Ataxia)
Maarssen NL-3607 EC
The Netherlands
31 346 563913
31 346 580417 (fax)
✉ ataxia@wxs.nl
http://home.wxs.nl/~ataxia

VSN - Werkgroep Ataxie van Friedreich
European Federation of Hereditary Ataxias (Euro-Ataxia)
Haagweg 306
Leiden NL-2324 NC
The Netherlands
31 71 5320660
http://www.vsn.nl

UK

Friedrich's Ataxia Group
European Federation of Hereditary Ataxias (Euro-Ataxia)
The Stable, Wiggins Yard,
Bridge Street
Godalming, Surrey GU7 1HW, UK
Contact: Chris Polhill
44 1483 417111
44 1483 424006 (fax)

USA

Ataxia MJD Research Project, Inc.
400 South El Camino Real,
Suite #640
San Mateo, CA 94402-1705
USA
Contact: Laura Denning
(650) 373-0674
(650) 342-8741 (fax)
✉LDenning@ataxiamjd.org
http://www.ataxia.mjd.org

National Ataxia Foundation
2600 Fernbrook Lane, Suite 119
Minneapolis, MN 55447-4752
USA
Contact: Donna Gruetzmacher
(612) 553-0020
(612) 553-0167 (fax)
✉naf@mr.net
http://www.ataxia.org
Resources: n, v, br, bk, ep, sg, pp, rs, fe, rg

DYSTONIA

AUSTRIA

Osterreichische Dystonie Gesellschaft
Austrian Dystonia Association
Ottakringer Str. 180
Vienna 1160, Austria
Contact: Christa Hafenscher
(43) 148-68637 (fax)

BELGIUM

Belgische Zelphulpgroep Voor Dystonie Patiïnten
Belgian Dystonia Association
Blokmakerstraat 6
Haasdonk 9120, Belgium
Contact: Christine Wauters
(32) 3 7755125
(32) 3 7755125 (fax)

BRAZIL

Associacao Brasileira dos Portadores de Distonias
Brazilian Dystonia Society
Al. Santos, 1780 13 andar
Sao Paolo
SP Cep: 01448-200, Brazil
Contact: Elenita Ferreira de Macedo
(55) 112871264 (phone/fax)
br, sg, rs, th

CHILE

Fundacion Distonia
Dystonia Foundation of Chile
Av. Irarrazaral 5185, Of. 311
Nunoa, Santiago, Chile
Contact: Benedicte De Pauw
(56) 22268874
(56) 22267346 (fax)
n, br, ep, sg, rs, fe

CROATIA

Hrvatska Grupa Za Istrazivanje Distonije
Croatia Dystonia Association
University of Zagreb, Kispaticeva 12
Zagreb 10000, Croatia
Contact: Prof. Maja Relja
(385) 01 233-5595 (phone/fax)

DENMARK

Dansk Dystoniforening
Danish Dystonia Association
Solhojpark 16
Farum DK - 3520, Denmark
Contact: Ulla Balser Poulsen
(45) 4295-5165 (fax)
Email: ullafarum@teliamail.dk
http://sunsite.auc.dk/dystoni/e_index.html

EUROPEAN

European Dystonia Federation
46/47 Britton Street
London ECIM 5UJ. UK
Contact: Alan Leng
(44) 171 490-5671
(44) 171 490-5672 (fax)

FRANCE

Association de Malades atteints de Dystonie (AMADYS)
20 rue de la Cote du Theil
Lavault Sainte Anne 03310, France
Contact: Marcel Besse
(33) 470-291-771 (phone/fax)
✉amadys@wanadoo.fr
http://perso.wanadoo.fr/amadys/
n, br, sg, rgj

KEY TO SERVICES

n	newsletter
v	video tape
a	audio tape
er	educator's resource materials
br	brochure, fact sheet
bk	book
ep	educational program
sg	support group meeting
pp	"Pen Pal" network
rs	referral service
th	telephone "hotline"
fe	fundraising event
rg	research grant

Ligue Francaise contre la Dystonie
27 rue du Bout des Creuses
Draveil 91210. France
(33) 169 83 23 39 (phone/fax)
✉lfcd@wanadoo.fr
http://perso.wanadoo.fr/lfcd/
n, br, bk, ep, sg, pp, th

GERMANY

Deutsche Dystonie Gesellschaft e. V.
German Dystonia Association
Bockhorst 45A
Hamburg 22589, Germany
Contact: Didi Jackson
(49) 40 870 21 33
(49) 40 870 56 02 (fax)
✉Deutsche-Dystonie@-online.de
n, br, sg, rs, pp, fe, rg

IRELAND

The Dystonia Society in Ireland
33 Larkfield Grove- Harold Cross
Dublin 6W, Ireland
Contact: Maria Hickey
(353) 196-4387

ITALY

Assoc. Italiana per la Ricerca Sulla Distonia
Italian Dystonia Association
Via Arturo Colautti 28
Rome 00152. Italy
Contact: Anna Florenzani
(39) 06 589-8727
(39) 06 580-3940 (fax)
✉segreteria.ard@iol.it
http://www.webzone.it/distonia/
n, br, bk, rs, th, fe

JAPAN

Dystonia Support Group of Japan
Ohtsu Central Post Office Box 11
Ohtsu City
Shiga 520, Japan
Contact: Masako Kaji
(81) 775-330-297
(81) 775-379-753 (fax)
n, br, sg, pp, th

NORWAY

Norsk Dystoniforening
Norwegian Dystonia Association
Sorliveien 59
Nittedal N-1482, Norway
Contact: Tore Wirgenes
(47) 35020538 (phone/fax)
✉norsk.dystoni.forening@online.no
http://home.sol.no/~torwi/
n, br, sg

SERBIA

Yugoslav Dystonia Association
Institute of Neurology, Dr. Subotica Nr. 6
Belgrade 11000, Serbia
Contact: Dr. Marina Svetel
381 11 685 554
381 11 661 720 (fax)
✉marinas@imi.bg.ac.yu
n, br, ep, sg, rs, th

SLOVENIA

Dystonia Association of Slovenia
Institute of Clinical Neurophysiology, University Medical Centre
Ljubljana 1525, Slovenia
Contact: c/o Dr. Zvezdan Pirtosek
(38) 661-316-152
(38) 661-302-771 (fax)
n, v, er, br, ep, sg

SOUTH AFRICA

South African Dystonia Association
PO Box 3160
Pinegowrie 2123s, South Africa
Contact: Maureen Langford
(27) 11 7878792 (phone/fax)
✉ parkins@global.co.za
n, v, br, sg, th, fe

SPAIN

Asoc. de Lucha contra la Distonia en EspaÒa
Spainish Dystonia Society
c/ Galileo, 69-1
Madrid 28015, Spain
Contact: Felisa Justo Alonso
(34) 91 7598866 (phone/fax)
✉alde@mx3.redestb.es
http://www.arrakis.es/~amolina/alde.htm
n, v, er, bk, sg, rs, th

SWEDEN

Svensk Dystoni Forening
Swedish Dystonia Society
Stjarngossevagen 108
Alvsjo 125 35, Sweden
Contact: Anders Silfors
(46) 8999956 (fax)
http://www.patientinformation.com/
www.pion.et
n, er, r, sg, th

SWITZERLAND

Schweizerische Dystonie Gesellschaft
Swiss Dystonia Association
Tramstrasse 39
Muttenz CH - 4131, Switzerland
Contact: Dr. Brigitte Gygli
(41) 614-616-993 (phone/voice)
n, v, br, ep, sg

THE NETHERLANDS

Nederlanse Verening van Dystoniepatienten
Netherlands Dystonia Association
Postbus 9345
Breda 4801 LH, The Netherlands
Contact: Louis Beduwe
(31) 76 522 7548
(31) 76 521 6495 (fax)
n, br, bk, sg, pp

UK

United Kingdom Dystonia Society
The Dystonia Society
46/47 Britton Street
London EC1M 5UJ, UK
Contact: Alan Leng
(44) 171 490-5671
(44) 171 490-5672 (fax)
http://www.connect.org.uk/merseyworld/glaxo/dystonia.html
n, v, er, br, ep, sg, pp, rs, th, fe, rg

USA

Dystonia Medical Research Foundation
One East Wacker Drive, Suite 2430
Chicago, IL 60601-1905, USA
Contact: Valerie Levitan, PhD
(312) 755-0198
(800) 361-8061 (in Canada)
(312) 803-0138 (fax)
✉dystonia@dystonia-foundation.org
http://www.dystonia-foundation.org/
n, v, a, er, br, bk, ep, sg, pp, rs, th, fe, rg

The Bachmann-Strauss Dystonia & Parkinson Foundation, Inc.
One Gustave L. Levy Place, Box 1490
New York, NY 10029, USA
Contact: Bonnie Strauss
(212) 241-5614
(212) 987-0662 (fax)
✉BAchmann_Strauss@smtplink.mssm.edu
http://www.dystonia-parkinsons.org
br, ep, fe, rg

BLEPHAROSPASM

See also: "Dystonia" for organizations that provide resources and services for all dystonias.

AUSTRALIA

Blepharospasm Support Group
Royal Victorian Eye & Ear Hospital, 32 Gisborne Street
East Melbourne
Victoria 3002, Australia
(61) 3-9929 8666
(61) 3-9665-7203 (fax)
✉jpritchard@rveeh.vic.gov.au

USA

Benign Essential Blepharospasm Research Foundation, Inc.
PO Box 12468
Beaumont, Texas 77726-2468
USA
Contact: Mary Lou Thompson
(409) 832-0788
(409) 832-0890 (fax)
✉bebrf@ih2000.net
http://www.blepharospasm.org/
n, v, a, br, bk, sg, rs, rg

SPASMODIC DYSPHONIA

See also: "Dystonia" for organizations that provide resources and services for all dystonias.

AUSTRALIA

Spasmodic Dysphonia Support Group
8 Corona Avenue, Roseville
New South Wales
Roseville 2069, Australia
Contact: Cynthia Turner
(61) 294-112-424 (fax)

NEW ZEALAND

NZ Spasmodic Dysphonia Patients' Network
15 Pluto Place
North Shore City
Auckland 1310, New Zealand
Contact: David Barton
(64) 9-482-1567
(64) 9-482-1284 (fax)
✉dsbarton@ihug.co.nz
n, br, sg

USA

National Spasmodic Dysphonia Association
One E. Wacker Drive, Suite 2430
Chicago, IL 60601-1905, USA
Contact: Valerie Levitan, PhD
(800) 795-NSDA (6732)
(312) 803-0138 (fax)
✉NSDA@aol.com
n, v, br, sg, pp, rg

TORTICOLLIS (CERVICAL DYSTONIA)

See also: "Dystonia" for organizations that provide resources and services for all dystonias.

AUSTRALIA

Australian Spasmodic Torticollis Association
PO Box 33
Westmead
New South Wales 2145, Australia
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GERMANY

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ESSENTIAL TREMOR

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International Association
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Fort Lee, NJ 07024
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PARKINSON'S DISEASE

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KEY TO SERVICES

n	newsletter
v	video tape
a	audio tape
er	educator's resource materials
br	brochure, fact sheet
bk	book
ep	educational program
sg	support group meeting
pp	"Pen Pal" network
rs	referral service
th	telephone "hotline"
fe	fundraising event
rg	research grant

FAEROES

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Faeroer
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National Parkinson Foundation, Inc.
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(613) 9828 7222
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Wahringer Guertel 18-20
Vienna A-1090, Austria
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(43) 140-400-3141 (fax)
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BELGIUM

Ligue Belge de la Sclerose en Plaques
173 bt 11 Avenue Plasky
Bruxelles B-1030, Belgium
(32) 2736-1638
(32) 2732-3959 (fax)

BRAZIL

ABEM
Rua Demostenes 283
Sao Paulo 04614-011, Brazil
(55) 11 531 1928
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✉abem@abem.org.br

CANADA

Canadian Multiple Sclerosis Association
2550 Argentia Road, Suite 230
Mississauga
Ontario L5N 5R1, Canada
(888) 395-CMSA (2672)
(905) 812-3522 (fax)

Multiple Sclerosis Society of Canada
250 Bloor St. East, Suite 1000
Toronto
Ontario M4W 3P9, Canada
Contact: Alistair Fraser
(416) 922-6065
(416) 922-7538 (fax)
✉info@mssoc.ca

CYPRUS

Cyprus MS Association
PO Box 6749
Nicosia 1647, Cyprus
(357) 2 525053
(357) 2 524287 (fax)
Email: alambra@spidernet.com.cy

CZECH REPUBLIC

Unie Roska - Czech MS Spolecnost
PO Box 38
Praha 2 120 00, Czech Republic
(422) 472 8619
(422) 248 12681 (fax)
✉irenamara@mbox.vol.cz

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The Danish MS Society
Mosedalvej 15
Copenhagen
Valby DK-2500, Denmark
(45) 3646-3646
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✉info@skleroseforeningen.dk

FINLAND

The Finnish MS Society
PL 15
Masku 21251, Finland
(358) 02 439 2111
(358) 02 439 2133 (fax)
✉ms-liitto@msl.pp.fi
http://www.ms-liitto.fi/english.htm
n, v, br, bk, ep, sg, fe, rg

FRANCE

Ligue Francaise Contre la SclÉrose en Plaq.
Tour CIT - BP 68, 3 rue de l'arrivÉe
Paris 75015, France
(33) 1-4322-4569
(33) 1-4232-5415 (fax)
✉lfsep@compuserve.com
www.handinews.com/LFSEP

LSFEP
17 blvd. Auguste Blanqui
Paris 75013, France
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GERMANY

Deutsche Multiple Sklerose Gesellschaft (DMSG) Bundesverbard e.V.
Vahrenwalder Str. 205-207
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GREECE

Greek MS Society
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HUNGARY

MS Society of Hungary
Department of Neurology, H-8001
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MS Society of India
c/o Motor Industries Co. Ltd., PB No 3000, Hosur Road, Adugodi
Bangalore 560 030, India
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(91) 80-227-2628 (fax)

INTERNATIONAL ASSOCIATION

International Federation of MS Societies
10 Heddon Street
London W1R 7LJ, UK
Contact: Richard Hamilton
(44) 171-734-9120
(44) 171-287-2587 (fax)
http://www.ifmss.org.uk

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MS Society of Ireland
2 Sandymount Green
Dublin 4, Ireland
(353) 1269-4599
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Israel MS Society
75 Yehuda Halevi Street
Tel Aviv 65796, Israel
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Vico Chiuso Paggi 3
Genova 16128, Italy
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(39) 10 247 0226 (fax)
✉aism@aism.it

JAPAN

Japan MS Society
4-1-2 Kotobuki, Taitoku
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(82) 338-42-4906 (fax)

LUXEMBOURG

Ligue Luxembourgeoise de la Sclerose en Plaques
BP 1444
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MEXICO

Asociacion Mexicana contra la EM
Calzada de Tlalpan 4515, Tlalpan - Toriello Guerra
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Society of NZ, Inc.
7th Floor, Rossmore House, 123 Molesworth Street, PO Box 2627
Wellington, New Zealand
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(64) 4499-4675 (fax)

NORWAY

Multipel Sklerose Forbundet i Norge
Sorkadalsveien 3
Oslo 3 0369, Norway
(47) 2260-4960
(47) 22256-7695 (fax)

POLAND

MS Society of Poland
Al. Jerozolimskie 65/79
Warsaw 00-697, Poland
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PORTUGAL

Sociedade Portuguesa de Esclerose Multiple
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(351) 1 868 38 95 (fax)

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Drustvo MS Slovenije
Maroltova ul. 14
Ljubljana 1113, Slovenia
(386) 61 168 7297 (phone/fax)

SOUTH AFRICA

South African Nat. MS Society
295 Villiers Road, Walmer
Port Elizabeth 6070, South Africa
(27) 4151-2900
(27) 4151-5705 (fax)
✉sanmss@jhb.lia.net

KEY TO SERVICES

n	newsletter
v	video tape
a	audio tape
er	educator's resource materials
br	brochure, fact sheet
bk	book
ep	educational program
sg	support group meeting
pp	"Pen Pal" network
rs	referral service
th	telephone "hotline"
fe	fundraising event
rg	research grant

SPAIN

ADEM
Avenida Donostiarra 26, 112, 1a
Madrid 28027, Spain
(34) 1103-6171 (phone/fax)

Asociacion Espanola de EM (AEDEM)
8 1 Centro Derecha
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Neurolog. Handikappades Riksforbund
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Stockholm S-103 65, Sweden
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(46) 824-1315 (fax)
✉nhr@nhr.se

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Zurich CH-8036, Switzerland
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(41) 1451-0939 (fax)
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Istanbul 80290, Turkey
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(90) 212-265-9420 (fax)

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MS Society of Great Britain and Northern Ireland
25 Effie Road
London SW6 1EE, UK
(44) 171-610-7171
(44) 171-736-9861 (fax)
✉ info@mssociety.org.uk
http://www.mssociety.org.uk

USA

Multiple Sclerosis Association of America
706 Haddonfield Road
Cherry Hill, NJ 08002
USA
Contact: Susan Freund
(800) 833-4MSA(4672)
(609) 661-9797 (fax)
✉msaa@msaa.com
http://www.msfacts.org
n, v, er, br, bk, ep, sg, pp, rs, th, fe

MULTIPLE SCLEROSIS FOUNDATION

6350 N. Andrews Avenue
Ft. Lauderdale, FL 33309
USA
(800) 441-7055 or
(954) 776-6805
(954) 938-8708 (fax)
✉ support@msfacts.org
http://www.msfacts.org
n, v, a, br, bk, sg, pp, rs, th, fe, rg

National Multiple Sclerosis Society
733 3rd Avenue, 6th Floor
New York, NY 10017-3288
USA
(800) FIGHT MS (344-4867)
(212) 986-3240
(212) 986-7981 (fax)
info@nmss.org
n, v, br, bk, ep, sg, rs, rg

ZIMBABWE

MS Society of Zimbabwe
PO Box 1234
Belvedere, Harare
Zimbabwe
(263) 4 740472 (phone/fax)

SPINAL CORD INJURY

USA

American Paralysis Association
500 Morris Avenue
Springfield, NJ 07081
USA
(800) 225-0290
(973) 379-2690
http://www.apacure.com
n, br, fe, rg

National Spinal Cord Injury Association
8300 Colesville Road, Suite 551
Silver Spring, MD 20910
USA
Contact: Diane Barry
(800) 962-9629
(301) 588-6959
http://www.spinalcord.org
br, bk, ep, pp

STROKE

UK

The Stroke Association
Stroke House, Whitecross Street
London EC1Y 8JJ, UK
Contact: Margaret Goose
(44) 171-566-0300
(44) 171-490-2686 (fax)
n, v, a, br, bk

USA

National Stroke Association
96 Inverness Drive East, Suite 1
Englewood, CO 80111-5112
USA
(800) STROKES or
(303) 649-9259
(303) 771-1887 (fax)
http://www.stroke.org
n, br, sg, ep, rs

Stroke Club International
805 12th Street
Galveston, TX 77550
USA
Contact: Ellis Williamson
(409) 762-1022
n, er, ep

TARDIVE DYSKINESIA/DYSTONIA

USA

Tardive Dyskinesia/Tardive Dystonia National Assoc.
4244 University Way NE,
PO Box 45732
Seattle, WA 98145-0732
USA
Contact: S. K. Kjaer
(206) 522-3166

TICS/TOURETTE'S SYNDROME

ARGENTINA

Tourette Syndrome Association of Argentina
Segurola 483, V.Sarmiento (1706)
Buenos Aires, Argentina
Contact: Stella Ortiz

AUSTRALIA

Tourette Syndrome Association of Australia
PO Box 1173
Maroubra
New South Wales 2035, Australia
Contact: Debbie Redelman
(61) 2311-2745 (phone/fax)
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BELGIUM

Vlaamse Vereniging Gilles de la Tourette
Nauwelaertstraat 7
Wynegem
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(32) 3353-6791 (phone/fax)
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206-194 Jarvis Street
Toronto
Ontario M5B 2B7, Canada
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(800) 361-3120
(416) 861-2472 (fax)
✉tsfc.org@sympatico.ca
www.tourette.ca
n, v, er, br, bk, ep, sg, th, fe, rg

DENMARK

Dansk Tourette Forening
Prestehusene 31
DK 2820
Denmark
Contact: Kjeld Christensen
(45) 4396-5709

FRANCE

Aftoc-Tourette
24, rue Leon Gambetta
Ronchin F 59790, France
Contact: Marc Lalvee
((33) 2085-9642

GERMANY

Tourette-Gesellschaft Deutschland e.V.
Von Siebold Str. 5
Gottingen 37085, Germany
Contact: Prof. Dr. A. Rothenberger
(49) 551-396727
(49) 551-398120 (fax)
✉arothen@gudg.de
http://www.bitwerk.de/tourette
n, v, er, br, bk, ep, sg

ICELAND

Tourette Samtokin a Islandi
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Reykjavik 105, Iceland
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(354) 551-4890
(354) 551-4580 (fax)
n, v, er, br, ep, sg, th

ISRAEL

TSA of Israel
PO Box 7018
Ramat Gan 52170, Israel
Contact: Anat Imber
(03) 9012956
n,er,br,sg,th

NEW ZEALAND

TSA of New Zealand
146 Weymouth Road, Manurowa
South Auckland, New Zealand
Contact: Carol Bridle

NORWAY

Norsk Tourett Forening
Brolandsveien 19 B
Oslo N-0980, Norway
Contact: Tom A. Wulff, President
(47) 2221-6506
(47) 2210-9921 (fax)

SOUTH AFRICA

Southern Africa Tourette Syndrome Institute
228 Oak Avenue
Ferndale 2194, South Africa
Contact: Johan van der Westhuizen
(27) 11-886-6353

SPAIN

Asociacion Espanola para Tics y Tourette
Gran Via de les Corts Catalanes, 562
pral. 2a
Barcelona 08011, Spain
(34) 451-5550
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SWEDEN

The Swedish Tourette Association
Soerkroken 2
Hjaetleby S-440, 74, Sweden
Contact: Ulf Christiansson
(46) 30467-8130 (phone/fax)

THE NETHERLANDS

TSA of the Netherlands
PO Box 925
Rhood 3160 AC, The Netherlands
Contact: Joop Van Hennik
(31) 18-901-3043

UK

Tourette Syndrome Association
1st Floor Offices, Old Bank
Chambers, London Road,
Crowborough
East Sussex TN6 2TT, UK
Contact: Paula Smith
(44) 1892-669151 (phone/fax)
✉TSA_UK@compuserve.com
http://TSA.mgh.harvard.edu

USA

Tourette Syndrome Association, Inc.
42-40 Bell Boulevard
Bayside, NY 11361
USA
Contact: Jennifer Cammon
(718) 224-2999
(800) 237-0717
(718) 279-9596 (fax)
✉tourette@ix.netcom.com
http://tsa.mgh.harvard.edu
n, v, a, er, br, ep, sg, rs, fe, rg

WILSON DISEASE

USA

Wilson's Disease Association
4 Navajo Drive
Brookfield, CT 06810-3124
USA
Contact: H. Ascher Sellner, MD
(800) 399-0266]
(203) 775-9666
(203) 743-6196
✉haseliner@worldnet.att.net
http://www.wilsonsdisease.org
n, a, br, sg, rs, th

NOTES:

State Directors of Special Education

Every state has a state education agency that is responsible for general supervision of the state's special education services for children and young adults with disabilities. Within each agency, one individual has the primary responsibility of overseeing these services. Usually, this person is called the State Director of Special Education. This individual—or his or her staff—can direct parents to appropriate local resources; is knowledgeable about the state's procedural safeguard system (the system for handling complaints, mediation, and due process procedures); and can offer other assistance as needed.

The listings in this directory were provided by the National Association of State Directors of Special Education [NASDSE, 1800 Diagonal Rd., Alexandria, VA 22314; (703) 519-3800 (voice); (703) 519-7008 (TTY); (703) 519-3808 (fax)], and are current as of November 1999.

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Carie Rothenbacher
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Shan Goff
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Bureau of Instruction Support and
Community Service
325 W Gaines St. Ste 614
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GEORGIA

Paulette Bragg
Georgia Dept. of Ed.
Div. for Exceptional Students
1870 Twin Towers East
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(808) 733-4841(fax)
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IDAHO

Nolene Weaver
State Dept. of Ed.
Special Ed. Section
650 W. State St.
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Boise, ID 83720-0027
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(208) 334-4664 (fax)

ILLINOIS

Gordon Riffel
Special Ed. Coordinator
Illinois State Board of Ed.
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100 N. First St.
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(217) 524- 6125(fax)
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MICHIGAN

Jacquelyn Thompson
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(651) 297-7368 (fax)
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State Dept. of Ed.
Office of Special Services
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Jackson, MS 39205-0771
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(601) 359-2198 (fax)

MISSOURI

Melodie Friedbach
Coordinator of Special Ed. Programs
Dept. of Elementary & Secondary Ed.
Div. of Special Ed.
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Jefferson City, MO 65102
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✉mfriedeb@mail.dese.state.mo.us

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Div. of Special Ed.
PO Box 202501
Helena, MT 59620-2501
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(406) 444-3924 (fax)

NEBRASKA

Gary M. Sherman
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Special Populations
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PO Box 94987
Lincoln, NE 68509-4987
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(402) 471-0117 (fax)

NEVADA

Gloria Dopf
Director, Nevada Dept. of Ed.
Educational Equity
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NEW HAMPSHIRE

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NEW JERSEY

Barbara Gantwerk
Director, NJ Dept. of Ed.,
Office of Special Ed. Programs
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Trenton, NJ 08625-0500
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NEW MEXICO

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NEW YORK

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NORTH CAROLINA

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Circle #56

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Circle #41

Safe and Secure on the Web

Pointers on Determining a Web Site's Credibility

by Vanessa B. Ira

With the dawning of the new century, the Internet has become a ubiquitous presence in homes, much like the telephone and TV. What this means for parents and professionals involved in the care of children with disabilities is empowerment made possible by such vast resources of information.

The last year alone has seen a proliferation of Web sites (those focused on disabilities number in the thousands, whether they be sites built for a specific disability association or a health site). How then does one determine which of those sites are credible, and therefore worth revisiting on a regular basis? The following are some pointers to consider in determining the credibility of relevant disability Web sites:

- **When on a Web site, click on the "About Us" or "Contact Us" links or buttons:** These links can give you an idea of who is on the team of people running a particular Web site. Many sites—particularly those that want to prove their credibility—will have a page describing the site's history, background and affiliations in its "About Us" section; It should also include an address, e-mail, or phone number in its "Contact Us" section.
- **Mine the Web's top search engines for additional research:** After you have reviewed any site's background, you can proceed to use search engines for supporting information. This is the exciting part of researching on the Web, where one can gain greater knowledge and perspective through the magic of hyperlinks.
- **Think "Links"**: Sites with good, usable information may have endorsements from prominent special needs organizations and/or have links to other Web sites with more information on the subject. Links to associations that are related to the subject or with educational or even government-supported institutions involved in that subject.
- **Word of mouth:** Ask friends and special needs associations for recommendations on Web sites they think are informative. Remember, you can also use the Internet to e-mail other people you think would be able to clue you in on the credibility of a particular Web site.
- **Content:** Aside from research, a site's credibility is reflected—as with books, magazines, and journals—in its editorial excellence. This means quality of content, down to the cleanliness of the page, which should have very little or no grammatical and typographical errors.
- **Check out how often the site is updated:** A site that is updated regularly with quality content—as some sites do on a daily or weekly basis—is most likely to be run by a team of people who care about its audience. **EP**

E-mail your comments on this article, or other ideas or suggestions for EParent.com, to: Vanessa B. Ira, Internet Projects Advisor and Consultant, at: vira@eparent.com. Or call (201) 634-6550 ext. 213.

Index of New Products

This index of New Products lists all the devices that appeared in the New Products column throughout 1999. The monthly column is compiled by ABLEDATA which maintains a database of assistive technology and rehabilitation equipment. The database contains information on more than 25,000 products for persons of all ages who have a physical, cognitive, or sensory disability. Products are chosen for this page by the ABLEDATA staff based on their specific applicability to or design for children with disabilities. ABLEDATA, operated by Macro International Inc., is funded by the National Institute on Disability and Rehabilitation Research.

For more information on assistive devices or to submit product information for the database contact: ABLEDATA, 8401 Colesville Rd., Ste. 200, Silver Spring, MD 20910; (800) 227-0216 or (301) 608-8998 (voice); (301) 608-8912 (TTY); (301) 608-8958 (fax); Web site: http://www.abledata.com.

Category	Subcategory	Name of Product	Manufacturer	Month/Year	Page
Baby Product	Cover	BABY SHIELD ®COVER	Outdoor Baby, Inc.	Sep-99	131
Clothing	Diaper	POOL PANT DIAPER™	Gabby's	Nov-99	91
Clothing	Pants	ABLEWEAR CARGO PANTS	AbleWear	Dec-99	91
Mobility	Bike	THE TRANSBAR POWER SYSTEM	TRB Systems, INC	Jul-99	79
Mobility	Chair	MULHOLLAND OMNI STANDER	Mulholland Positioning System	Feb-99	75
Mobility	Cart	INNOVATIVE PRODUCTS GO-KART	Innovative Products, Inc.	Nov-99	91
Mobility	Scooter	TRAVELMATE™	Amigo Mobility International, Inc.	Jul-99	79
Mobility	Stander	EASYSTAND QUICKLIFT™	Altimate Medical, Inc.	Sep-99	131
Mobility	Stander	MULHOLLAND OMNI STANDER	Mulholland Positioning System	Apr-99	99
Mobility	Stander	TNT LITE	Gunnell Inc.	Apr-99	99
Mobility	Stander	EASYSTAND 6000 GLIDER	Altimate Medical Inc.	May-99	111
Mobility	Stroller	WENZELITE™ MSS TRAVELER	Wenzelite Medical Supply Corp.	Oct-99	107
Mobility	Stroller	WENZELITE UMB ROLLER	Wenzelite Medical Supply Corp.	Nov-99	9
Mobility	Stroller	PIXI PUSHCHAIR	Sammons Preston	Jun-99	103
Mobility	Toilet Transfer	REVERSIBLE TOILET TRANSFER SEAT	Maddak Inc.	Feb-99	75
Mobility	Wheelchair	SEEKER ™	Jason Narine Enterprise	Aug-99	91
Mobility	Wheelchair	THIS IS A "HOLD UP"!®	Kristi Care	Aug-99	91
Mobility	Wheelchair	THE CONVAID CRUISAIRE	Convaid	Dec-99	91
Mobility	Wheelchair	STARLIGHT	Global Power Systems, Inc.	Apr-99	99
Mobility	Wheelchair	KILLI-KART	Disability Option, Inc.	Apr-99	99
Mobility	Wheelchair	SMALL FRY	Freedom Designs, Inc.	Jul-99	79
Positioning	Chair	THE RIFTON CHAIR	Rifton Chair	Nov-99	91
Sporting Equip.	Training Pad	SUPRACOR® BAREBACK & TRAINING PAD	Supracor	Apr-99	99
Technology	Blocks	THAT BOOK THING™	ArtVoice	Jun-99	103
Technology	Communicator	TECH/SPEAK	Mayer-Johnson Co.	Jun-99	103
Technology	Communicator	TECH/FOUR™	Mayer-Johnson Co.	May-99	111
Technology	Communicator	HAWK 2 & HAWK 3 COMMUNICATION DEVICES	Wayne County Regional Educational Service Agency	Aug-99	91
Technology	Handle	GADJIT™ CAN HANDLE	McNaughton Inc.	Sep-99	131
Technology	Lap tray	LAP WIZARD™	Wizard Works	Oct-99	107
Technology	Music	KIDDIE CAR TUNES™	Sphere Multimedia Technologies	Oct-99	107
Technology	Pen	QUICKTIONARY™ READING PEN™	Educational Product Division Seiko Instrument	Feb-99	75
Technology	Spoon	STEADYSPOON™	Handle With Care	Jun-99	103
Technology	Switches	CREDIT CARD SWITCH	Enabling Devices/ Toys for Special Children	May-99	111
Technology	Watch	VIBRALITE 3™	Global Assistive Devices Inc.	Sep-99	131
Toys	Blocks	PEACEFUL PLANET™ SURPRISE INSIDE BLOCKS	Fisher-Price Inc.	Aug-99	91
Toys	Blocks	CHILD GUIDANCE™ TALKING PHONICS BLOCKS	Jakks Pacific, Inc	Dec-99	91
Toys	Dolls	MIX-M-UPS ™	Golden Kids	Oct-99	107
Toys	Dolls	DOWNI CREATION™ DOLLS WITH DOWN SYNDROME	Downi Creations	Jul-99	79
Toys	Game	ALPHABET TOSS N' PLAY	Learning Resources	Feb-99	75
Toys	Game	THINKIN THIINGS® FRIPPLETOWN™	Edmark®	Jun-99	103
Toys	Game	STACKING SNAIL	Learning Curve International L.L.C	Jul-99	79
Toys	Kids Gym	TINY LOVES® GYMINI DELUXE™ 3-D ACTIVITY	Maya Group, Inc.	Dec-99	91
Toys	Stuffed animals	SING N GIGGLE ™WINNIE THE POOH® CHARACTERS	Mattel Inc.	Oct-99	107
Toys	Stuffed animals	WEE CARE™ PACIFIER HOLDER BEARS	Questech International	Nov-99	91
Toys	Switches	ANIMAL SWITCHES	Enabling Device/Toys for Special Children	Aug-99	91
Toys	Talking Scanner	FISHER-PRICE SCANNIN" TALKIN' CHECKOUT	Fisher-Price Inc.	Dec-99	91
Toys	Video Game	WHEELS'©	RJ Cooper & Assoc	May-99	11

For people, by people, about people

The changing climate of healthcare funding creates challenges for children and families trying to access all necessary primary and specialty healthcare services. This Bill of Rights is presented to assist those who participate in assuring access to excellent healthcare services for all children with special healthcare needs and their families.

Recently, 20 family members and professional leaders from the areas of primary and specialty care pediatrics, public policy, and family support met to discuss and define the values, principles, and strategies necessary to affect positive change in the field of specialty healthcare and support services for children with special healthcare needs and their families. The participants represented pediatrics, developmental disabilities, mental health, child welfare, and long-term special healthcare needs.

Following are the values and principles adopted at the gathering:

- **Each child is unique and requires individualized attention in the process of planning, evaluation, and implementation of healthcare services.**
- **Families are assumed to be experts regarding their children and are willing to offer their skills, knowledge, and experience to any healthcare process.**
- **Healthcare for children must be determined by informed family choice.**
- **Partnerships of families and professionals are essential to the delivery of quality health care.**

The following Bill of Rights is a result of these discussions. We hope this Bill of Rights will be considered in all public health policy discussions and be used to influence healthcare policy and financing to assure access to primary and specialty healthcare services for all children with special healthcare needs and their families.

This [illegible] supported by the Institute on Disability/UAP of the University of New Hampshire, Center for Genetics and Child Development, and The Hood Center for Children & Families, Dartmouth Medical School, and Institute for Health Law

Preamble

Over the past decade, effective approaches to support families and children with special healthcare needs have emerged. Today, these family-centered, community-based approaches designed to improve health outcomes are in jeopardy due to the changing funding mechanisms in health care, most notably managed care. Current managed care practices shift decision making from the local level to remote and impersonal organizations, create significant access problems for persons with complex and significant needs, contain inadequate consumer safeguards, and are inconsistent with specialty healthcare needs of children and families. Families in partnership with their physicians and other healthcare providers seek to maintain the gains realized from family-centered and community-based approaches and see continued development of quality health and related support services.

Bill of Rights

All children and families have a right to:

1 Choice among quality family-centered, culturally-sensitive, community-based, comprehensive, and coordinated healthcare services based on the needs of the child and the preferences of the family.

2 Choice among quality child and family-centered mental health and/or behavioral health services and family support.

3 Primary and specialty healthcare services which emphasize typical community-based service options for children.

4 Information regarding the relevant knowledge, skills, and practices of primary and specialty healthcare providers in regard to family-centered services, comprehensive care coordination, culturally competent services, specific childhood medical conditions, and the delivery of and support for community-based services.

5 Timely referral to a choice of specialty healthcare providers based on the needs of the child and without burdensome financial disincentives or authorization processes for families and primary care providers.

6 Assurance of timely communication between the child's primary care provider and all specialty and allied healthcare providers.

7 Family-centered and child-oriented appeal processes for conflict resolution with any insurance company or public funding source.

8 Primary, allied, and specialty healthcare services without the possibility of exclusion from insurance or similar financial support based on a "pre-existing condition," such as the presence of a developmental disability, emotional/behavioral challenge, or other special healthcare need.

9 Primary care providers who are offered incentives, rather than disincentives, to serve children with special healthcare needs.

10 Financing mechanisms (e.g. "capitation rates") that assure access to medically necessary specialty healthcare and related services.

11 Appropriate mileage reimbursement for families who are required by their insurance plan to travel beyond 50 miles to access specialty healthcare services.

Reprinted courtesy of the Institute on Disability/UAP of the University of New Hampshire.

and Ethics at Franklin Pierce Law Center. Send comments to UAP Policy Group, Institute on Disability, [illegible] Suite 101, Durham, New Hampshire [illegible] Website Address: [illegible]

Managing with Managed Care Organizations:

A compass for navigating strange new waters.

by Fern R. Potvin

In the course of only a few years, we have seen a rapid transition from traditional fee-for-service medicine to managed care. This shift has forced a complete reorientation in thinking about the healthcare delivery system in the US. Under the fee-for-service system, the insurer was chosen by an employer, a union, or an affinity group such as a professional organization or a college alumni association. Now these same entities pick the managed care organization (MCO), though sometimes the selection of MCOs they can choose among are restricted by state insurance regulations. Individuals, by contrast, are offered only a limited selection—if any—among the final choices.

MAKING SENSE OF IT ALL

Both fee-for-service and managed-care systems establish available benefits and co-payments, and set caps on reimbursement. The two big differences between the old system and the new—the major changes that have engendered so much controversy—are choice and constraints. MCOs specify which primary-care physicians are "approved" providers and then require that they serve as "gatekeepers" who must approve any visits to specialists.

To most consumers these restrictions are just an inconvenience. To people with disabilities and their families, the limits can be a nightmare; they disrupt longstanding and effective patient-physician relationships, eliminate access to specialists, and can result in denial of treatment. "Managed Care and Children with Chronic Illness or Disabilities" by Elizabeth J. Jameson, JD, (Exceptional Parent, September 1999; see box at end of article for order information) examined this situation and offered suggestions to lessen its impact. One useful strategy is to know an MCO's policies and procedures before seeking treatment. This gives the consumer an opportunity to research the most appropriate primary-care physician, for example, or even allow arranging for preapproval of crucial treatments.

Another resource is the National Committee for Quality Assurance (NCQA), which has a wealth of information that can help (see the sidebar on the following page for information on how to contact the NCQA or access their Web site). Created in 1991, the NCQA is a non-profit organization governed by a Board of Directors that includes employers, consumer and labor representatives, health plans, quality experts, health-policy makers, and physicians. Its mission is the establishment of standardized, objective information about MCOs and development of a system of performance measures and accreditation. The accreditation program is voluntary, but almost half the country's MCOs—covering 75 percent of those enrolled in managed care—participate. Qualifications are rigorous; more than 60 different standards, falling into five broad categories, are reviewed during the accreditation process, which also examines member and employer satisfaction with the plan. Here are brief summaries of the five categories:

Access and service: covers general availability of care, including freedom of participating physicians to discuss all available treatment options. Also deals with consumer-reported problems in getting care and how well the plan follows up on grievances.

Qualified Providers: investigates how qualifications of doctors and nurses are assessed, including how often licenses and training are reviewed. Includes consumers' ratings of providers.

Staying Healthy: determines whether the plan helps people maintain good health and avoid illness, stressing preventive care, and whether patients are being given appropriate testing and screening.

Getting Better: outlines how well consumers are cared for when they do become ill, and how new procedures, treatments, and drugs are evaluated for safety and efficacy and then put into practice.

Living with Illness: discusses evaluation and treatment of chronic conditions, and indicates whether the plan has disease-management specialists or teams to assist consumers in

managing conditions such as asthma.

The list of evaluated plans is updated monthly and the results are made available on the 15th of the following month; all plan-specific information shown in this article is from the October 31, 1999 update. When an evaluation is complete, NCQA assigns the plan an accreditation status:

- **Accredited**, **commendable**, or **excellent** indicate that the plan meets, exceeds, or significantly exceeds requirements.
- **Provisional** status means that a plan meets some, but not all, of the standards.
- A plan that has been **denied** accreditation does not meet the requirements.

A current list of plans whose applications for accreditation have been denied is below. If your plan is on this list, tell your benefits manager, union representative, or association membership director **immediately**.

Plans denied NCQA accreditation:
UHP Healthcare, Inglewood, CA HMO
ANTERO Health Plans, Denver, CO HMO
Blue Cross Blue Shield of Delaware, Wilmington, DE HMO/POS Combined
Prudential HealthCare, Tampa Bay, FL HMO/POS Combined
Welborn Health Plans, Evansville, IN HMO/POS Combined
WellCare of New York, Inc., Kingston, NY HMO/POS Combined
Independent Health - Hudson Valley, Tarrytown, NY HMO
AultCare Corporation, Canton, OH HMO/POS Combined
AultCare Corporation, Canton, OH PPO
Qual-Med Oregon Health Plan, Portland, OR HMO
QualMed Plans for Health of Ohio and West Virginia, Inc., Pittsburgh, PA HMO
Emphesys Wisconsin Insurance Company, Green Bay, WI HMO/PPO
CareNetwork, Inc. Milwaukee, WI HMO/POS
CombinedFamily Health Plan Cooperative, Milwaukee, WI HMO

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Exceptional Parent, 555 Kinderkamack Rd.,Oradell, NJ 07649
Bulk orders will incur a charge. Please call Glenn Collucci, (800) EPARENT (372-7368) ext. 202, with your bulk order.

NCQA has evaluated and accredited dozens of health plans, far too many to list here. The following is a list dividing the U.S. into seven geographic regions and containing a few of the larger plans in each region along with their current status. Any states not included did not have plans shown on the NCQA list. National Committee on Quality Assurance, 2000 L St., NW Ste. 500,Washington, DC 20038; (202) 966-3500; (202) 955-3599 (fax); Web site: http://www.ncqa.org

New England CT, MA, ME, NH, RI, VT

Aetna US Healthcare	commendable
Blue Cross and Blue Shield	excellent
CIGNA	commendable
Harvard Pilgrim	excellent
Oxford	accredited

Middle Atlantic DE, MD, NJ, NY, PA, VA, WV

Aetna US Healthcare	commendable
CIGNA	commendable: NJ, NY, VA; accredited: MD
Kaiser Foundation Health Plan	commendable
Oxford	accredited
Prudential	commendable

Southeast AL, AR, FL, GA, KY, LA, MS, NC, SC, TN

Aetna US Healthcare	commendable
Blue Cross and Blue Shield	commendable
CIGNA	commendable: FL, LA, NC, TN; accredited: GA
Humana	commendable
Kaiser Foundation Health Plan	commendable
Prudential	commendable; accredited: Jacksonville, FL

Midwest IA, IL, IN, KS, MI, MN, MO, OH, WI

Aetna US Healthcare	commendable
Blue Cross and Blue Shield	commendable
CIGNA	commendable
Humana	commendable
Kaiser Foundation Health Plan	commendable
Prudential	commendable: MO; accredited: OH

Mountains CO, ID, NE, NV, UT

CIGNA	commendable
Kaiser Foundation Health Plan	commendable
PacifiCare	commendable
Prudential	commendable
United HealthCare	commendable

Southwest, AZ, NM, OK, TX

Aetna US Healthcare	commendable
CIGNA	commendable; accredited: South TX
NYLCare	commendable
PacifiCare	commendable
Prudential	commendable

Pacific CA, HI, OR, WA

Aetna US Healthcare	commendable
Kaiser Foundation Health Plan	commendable; excellent: HI
PacifiCare	commendable
Prudential	commendable
United HealthCare	commendable

Family Voices State Contact List

The following list of Family Voices State Contacts was provided by Family Voices. Family Voices is a national grass roots clearing-house for information and education about ways to assure and improve healthcare for children with disabilities and chronic conditions. Their network includes families, a volunteer Coordinator in each state, regional Coordinators, and staff. Members of the network serve on local, state, and national boards and task forces; as staff for state health agencies or parent organizations; and as advisors to private and public health systems and research projects. Their mission is to bring the family perspective to policy discussions and decisions. Below are the group's contacts for each state. For the states with no contacts listed, please call the National Family Voices Office at: (888) 835-5669 for information or reach them at :PO Box 769, Algodones, NM 87001; e-mail: kidshealth@familyvoices.org; Web site: http://www.familyvoices.org.

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ARIZONA	CHAVA CANNON	(602) 277-7504	FAMVOICES@AOL.COM
ARKANSAS	RODNEY FARLEY	(501) 682-1461	REFARLEY@JUNO.COM or RFARLEY@KIDCARE.NET
CALIFORNIA	JUNO DUENAS	(415) 282-7494	SFCDMISS@AOL.COM
COLORADO	SALLY L. MAXEY	(303) 321-2260	SALLYMAX@USWEST.NET
CONNECTICUT	MOLLY COLE	(860) 545-9023	MCOLE@CCMCKIDS.ORG
DELAWARE	BETH MACDONALD	(302) 697-1976	BMACDON@DEN.K12.DE.US
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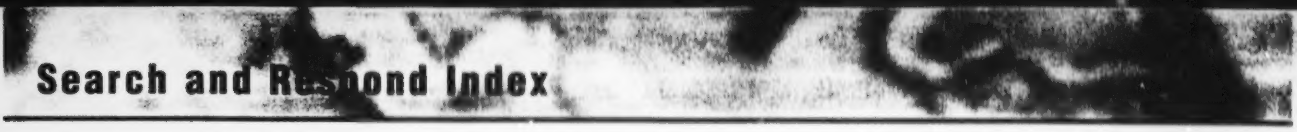
MASSACHUSETTS	BARBARA POPPER	(617) 236-7210 X 122	BPOPPER@FCSN.ORG
MICHIGAN	RAMONA ADAMS	(800) 292-7851 X110	RADAMS@VOYAGER.NET
MINNESOTA	CAROLYN ALLSHOUSE	(612) 821-9892	CALLSHOUSE@PACER.ORG
MISSISSIPPI	ARETHA LEE	(601) 714-5707	
MISSOURI	CALL FAMILY VOICES	(888) 835-5669	
MONTANA	CALL FAMILY VOICES	(888) 835-5669	
NEBRASKA	JUDY QUEST	(402) 551-4185	DEARHEART@HOME.COM
NEVADA	NEVADA PARENT NETWORK	(775) 784-4921 X2352	
NEW HAMPSHIRE	MARTHA JEAN MADISON	(800) 232-0986 X33	MJM10KIDS@AOL.COM
NEW JERSEY	LAUREN AGORATUS	(609) 584-5779	
	LOUISE MCINTOSH	(609) 277-2883	
NEW MEXICO	PRO	(800) 524-5176	NMPROTH@AOL.COM
NEW YORK	RUTH WALDEN	(518) 474-2001	RXW03@HEALTH.STATE.NY.US
NORTH CAROLINA	RICHARD CLARK	(828) 687-0331	RCLARK2952@AOL.COM
NORTH DAKOTA	DONENE FEIST	(701) 493-2333	FEIST@DAKTEL.COM
OHIO	KATHY BACHMAN	(614) 752-2930	BACHMANNHO@AOL.COM
OKLAHOMA	LYN THORESON	(405) 373-3300 (800) 766-2223	LYNT@HEALTH.STATE.OK.US
OREGON	LAUREN BRIDGE	(503) 215-2504	LBRIDGE@PROVIDENCE.ORG
PENNSYLVANIA	MARYBETH AZHORCHAK	(724) 538-4458	QZAHORCHAK@AOL.COM
	AND SUE BADEAU	(202) 224-7515	Sue_Badeau@rockefeller.senate.gov
RHODE ISLAND	DAWN WARDYGA	(401) 727-4144 X58 or (800) 464-3399 X58 (RI ONLY)	FAMILY VOICES@RIPIN.ORG
SOUTH CAROLINA	SUE SLATER	(803) 736-4595	SUE3403@MSN.COM
SOUTH DAKOTA	BARB BECK	(605) 361-3171	
	BEV PETERSON		
TENNESSEE	DARA HOWE	(615) 383-9442	FAMVOICTN@AOL.COM
TEXAS	COLLEEN HORTON	(512) 327-8636	CLKHORT@AOL.COM
UTAH	GINA POLA-MONEY	(801) 272-1051	UTAHFAMILYVOICES@JUNO.COM
VERMONT	MAUREEN MITCHELL	(802) 823-5256	MEM@TOGETHER.NET
VIRGINIA	HEATHER B. MCCABE	(703) 960-2361	DRMOM9@JUNO.COM
WASHINGTON	JUDIE EBBERT-RICH	(360) 866-8254	JUDIERICH@OLYWA.NET
WEST VIRGINIA	BOB CRAIG	(304) 293-1495	RCRAIG@WVU.EDU
WISCONSIN	LIZ HECHT	(608) 263-7148	HECHT@WAISMAN.WISC.EDU
WYOMING	DIANE MAGILL	(307) 777-3637	DMAGIL@MISSC.STATE.WY.US



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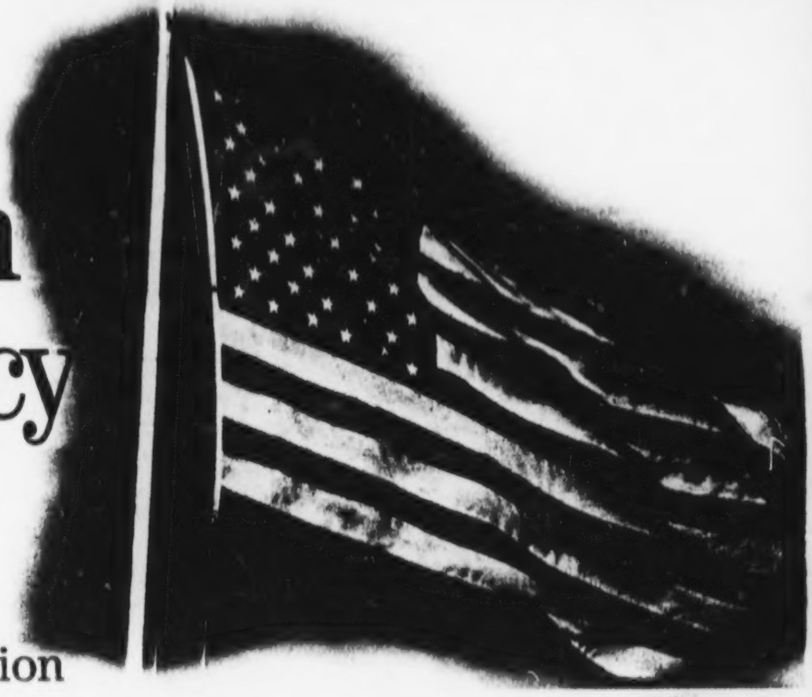
The Protection & Advocacy System:

Offering Special Attention to Special Education



One day, a mom went to pick up her son from school. As she roamed through his classroom, seeing other children laughing and playing, she could not find him. "Where's Scott?" she asked. All eyes went to the six-by-seven-foot grey metal box at the back of the room. Some of the kids in the class giggled, some even laughed outright. As she looked down into the box through the mesh wire that served as the "roof" of the box, she found her son looking up at her.

Scott has a disorder that sometimes causes him to have mild behavior problems. In order to "teach" Scott to behave, his school built this box and put him in it for hours at a time. No one else went into the box when they did not behave. Scott's parents turned to their state's Protection and Advocacy (P&A) office for help.

P&As are federally mandated to provide legally-based advocacy services to people with disabilities in each state and territory. P&As, collectively, are the largest providers of legally-based advocacy services to people with disabilities nationwide. Last year, P&As assisted almost 70,000 individual clients and touched the lives of more than three million people on disability issues.

What happened to Scott? As part of Scott's Individualized Education Program (IEP) that is required under the Individuals with Disabilities Education Act (IDEA), the school was supposed to provide him with a behavior management plan, not a prison. The school argued that the box complied with state law and satisfied their obligation to teach Scott to behave. The P&A convinced the school that it must teach Scott what to do and not just punish him. After much negotiation, the school removed the box. Now when Scott misbehaves, he is punished using the method described in his behavior management plan.

SPECIAL EDUCATION BY THE NUMBERS

Cases similar to that of Scott—ensuring that children with disabilities receive the appropriate services under IDEA — account for nearly 35 percent of P&A cases. Still there is so much more that needs to be done. According to a report by the Office of Special Education Programs (OSEP) in the U.S. Department of Education, many states are still serving children with disabilities in segregated settings (meaning that they learn in classrooms or schools that are separate from children without disabilities). Using the most recent data available, OSEP reported to Congress on how states are doing. For children with disabilities, ages 6 to 11, the U.S. Virgin Islands are serving 75 percent in segregated classrooms and the District of Columbia is serving more than 40 percent the same way. On the flip side, in Vermont, 91 percent of the children are in integrated settings (children with disabilities learn in the same classroom as students without disabilities) and in North Dakota the fugure is 84 percent.

P&As primarily advocate on behalf of special education students through funds from two federal programs - Protection and Advocacy for People with Developmental Disabilities (PADD) and Protection and Advocacy for Individual Rights (PAIR). These two programs join two other programs - Protection and Advocacy for Individuals with Mental Illness (PAIMI) and the Client Assistance Program (CAP) - to complete the entire P&A System.

THE LIVES WE TOUCH

In Wichita, Kansas the school board voted to cut the funds for speech and occupational therapy (OT) programs. That meant 200 students who had been receiving speech and OT at school to help them with their school work (many also received services outside of school), could no longer receive these services. They would fall farther behind their classmates each year. The P&A stopped the school board by filing two class action lawsuits in May, 1997. Shortly after the lawsuits were filed, the district reinstated the speech and OT programs. The cases settled in October, 1997, with an agreement by the school district to offer services during the summer to the students whose services were cut.

Aaron, a young child in Wyoming, lives with foster parents who make all of the everyday decisions for him that parents ordinarily make. The school district insisted that it had the right to select a separate parent surrogate to make decisions about Aaron's educational program, and filed an action in court requesting to enforce that right. If the school district had won, Aaron's foster parents would have had no say in decisions about what kind of school he would attend, what types of teachers and services he would have, etc. The P&A advocated for Aaron's foster parents to be involved in decisions about his education. After a hearing, the Court held that the child's needs take precedence over the school district's interpretation of state education rules and regulations. The court also decided that whether a foster parent may serve as the parent of the child for purposes of planning his educational program is a determination to be made on a case by case basis. Now, Aaron's foster parents can decide what's best for Aaron at school.

In Arizona, the school district had a policy of ending all educational services for certain students with disabilities who had been expelled from school, despite the fact that the law clearly states that this is illegal. No child who is eligible for special education may be completely cut off from an education. The P&A filed a lawsuit in federal court, challenging the school district's policy. The court ruled that the school district's policy violated the IDEA, a federal special education law. The judge found that services for students who are suspended for long periods of time or expelled for conduct related or unrelated to their disability, can never be completely cut off from education services. Additionally, the judge said that getting an education is a fundamental right under the Arizona Constitution. The school district decided not to appeal and is negotiating a settlement.

LEARN MORE ABOUT P&As

P&As all over the country are working on a variety of cases with a common theme—ensuring that children in special education are receiving the services to which they are entitled under IDEA. The P&A System provides a unique and effective resource for disability rights advocacy and education. People with disabilities, their family members and representatives are encouraged to make use of these services. Consistent with available resources and priorities established by the community, the P&A will make every effort to provide appropriate assistance to remedy the situation.

For additional information about the P&A System, including the location of all P&As nationwide, contact the National Association of Protection and Advocacy Systems, at (202) 408-9514 (voice) or 202-408-9521 (TTY), or visit the P&A Web page, at http://www.protectionandadvocacy.com. For information about an individual case or local resources,see the directory of state listings below and on the following page.

State Protection And Advocacy Agencies For Persons With Developmental Disabilities, Mental Illness And The Client Assistance Program 1999

ALABAMA

CAP
State of Alabama Client Assistance Program
2125 East South Blvd.
Montgomery, AL 361116-2454
(800) 228-3231 (voice or TDD)
(334) 281 2276 (voice or TDD)
✉sacap@hotmail.com
http://members.theglobe.com/jerlam/

PADD/PAIMI/PAIR
Alabama Disabilities Advocacy Program
The University of Alabama
Box 870395
Tuscaloosa, AL 35487-0395
(800) 826-1675 (205)348-4928
(205) 348-9484 (TTD)
(205) 348-3909 (fax)
✉adap@law.ua.adu
http://www.adap.net

ALASKA

CAP
ASIST
2900 Boniface Parkway, #100
Anchorage, AK 99504-3195
(907) 333-2211
(907) 333-1186 (fax)

PADD/PAIMI/PAIR
Disability Law Center of Alaska
615 E. 82nd Ave., St. 101
Anchorage, AK 99518
(800) 478-1234
(907) 344-1002 (voice/TDD)
(907) 349-1002 (fax)
✉cklinger@dlcak.org
http:// www.dlcak.org

AMERICAN SAMOA

CAP/PADD/PAIMI/PAIR
Client Assistance Program and Protection & Advocacy
PO Box 3937
Pago Pago,
American Samoa 96799
(011) 684-633-2441
(011) 684-633-7286 (fax)
✉opad@samoatelco.com

ARIZONA

CAP/PADD/PAIMI/PAIR
Arizona Center for Disability Law
3131 North Country Club, Ste. 100
Tucson, AZ 85716
(520) 327-9547 (voice/TDD)
(520) 323-0642 (fax)
✉lcohen@acdl.com
http://www.nau.edu/~ihd/acdl.html

ARKANSAS

CAP/PADD/PAIMI/PAIR
Disability Rights Center, Inc.
Evergreen Place, Ste. 201
1100 North University
Little Rock, AR 72207
(800) 482-1174
(501) 296-1775 (voice/TDD)
(501)296-1779 (fax)
✉panda@advocacyservices.org
http:// www.advocacyservices.org

CALIFORNIA

CAP
Client Assistance Program
2000 Evergreen St., 2nd Floor
Sacramento, CA 95815
(800) 952-5544 (916) 263-7372
(916) 263-7464 (fax)
✉smentkow@rehab.cahwnet.gov
http:// www.rehab.cahwnet.gov

PADD/PAIMI/PAIR
Protection & Advocacy, Inc.
100 Howe Ave., Ste. 185N
Sacramento, CA 95825
(800) 776-5746
(916) 488-9955 Admin. Off.
(916) 488-9950 Legal Off.
(916) 488-2635 (fax)
✉legalmail@pai-ca.org
http://www.pai-ca.org
California P&A Homepage

COLORADO

CAP/PADD/PAIMI/PAIR
The Legal Center
455 Sherman St., Ste. 130
Denver, CO 80203
(800) 288-1376
(303) 722-0300 (voice/TDD)
(303) 722-0720 (fax)
✉hn6282@handsnet.org

CONNECTICUT

CAP/PADD/PAIMI/PAIR
Office of P&A for Persons with Disabilities
60B Weston St.
Hartford, CT 06120-1551
(800) 842-7303 (statewide)
(860) 297-4300 (860) 566-2102 (TDD)
(860) 566-8714 (fax)
✉hn2571@handsnet.org
http://www.state.ct.us/opapd

DELAWARE

CAP
Client Assistance Program
United Cerebral Palsy, Inc.
254 East Camden-Wyoming Ave.
Camden, DE 19934
(800) 640-9336 (302) 698-9336
(302) 698-9338 (fax)
✉capucp@magpage.com

PADD/PAIMI/PAIR
Disabilities Law Program
913 Washington St.
Wilmington, DE 19801
(302) 575-0660 (voice/TDD)
(302) 575-0840 (fax)
✉Brian_J_Hartman@diamond.net.udel.edu

DISTRICT OF COLUMBIA

CAP/PADD/PAIMI/PAIR
University Legal Services
300 I St., NE, Ste. 202
Washington, DC 20002
(202) 547-0198
(202) 547-2083 (fax)
✉jbrown@uls-dc.com

FLORIDA

CAP/PADD/PAIMI/PAIR
Advocacy Ctr. for Persons w/Disabilities
2671 Executive Center, Circle West
Webster Building, Ste. 100
Tallahassee, FL 32301-5024
(800) 342-0823
(800) 346-4127 (TDD)
(850) 488-9071
(850) 488-8640 (fax)
http://www.advocacycenter.org

National Association of Protection & Advocacy Systems

GEORGIA

CAP
Georgia CAP
123 N. McDonough
Decartur, GA 30030
(404) 373-3116
(404) 373-4110 (fax)
✉GaCAPDirector@theOmbudsman.com
URL:http://www.theOmbudsman.com/CAP/

Department of Human Resources
Division of Rehab. Service
2 Peachtree St., NW, Room 23-307
Atlanta, GA 30303
(404) 657-3003 (404) 657-7855 Fax

PADD/PAIMI/PAIR
Georgia Advocacy Office, Inc.
100 Crescent Centre Parkway,
Ste. 520
Tucker, GA 30084
(800) 537-2329
(404) 885-1234 (voice/TDD)
(770) 414-2948 (fax)
✉ringerj@earthlink.net
✉olwyn@earthlink.net
http://ul451.gsu.edu/gao/

GUAM

CAP
Parent Agencies Network
PO Box 23474
GMF, Guam 96921
(011) 671 649-1948
(011) 671-472-2568 (fax)

PADD/PAIMI/PAIR
The Advocacy Office
Reflection Center, Ste. 204
222 Chalan Santo Papa
Agana, Guam 96910
(011) 671-472-8985/6/7
(011) 671-472-8988 (TDD)
(011) 671-472-8989 (fax)
✉hn5986@handsnet.org
✉advocate@kuentos.guam.net

HAWAII

CAP/PADD/PAIMI/PAIR
Protection & Advocacy Agency
1580 Makaloa St., Ste. 1060
Honolulu, HI 96814
(808) 949-2922 (voice/TDD)
(808) 949-2928 (fax)
✉pahi@pixi.com
http://www.pixi.com/~pahi

IDAHO

CAP/PADD/PAIMI/PAIR
Co-Ad, Inc.
4477 Emerald, Ste. B-100
Boise, ID 83706
(800) 632-5125
(208) 336-5353 (voice/TDD)
(208) 336-5396 (fax)
✉coadinc@cyberhighway.net
http://users.moscow.com/co-ad

ILLINOIS

CAP
Illinois Client Assistance Program
100 N. First St., 1st Fl
Springfield, IL 62702
(217) 782-5374
(217) 524-1790 (fax)

PADD/PAIMI/PAIR
Equip for Equality, Inc.
11 East Adams, Ste. 1200
Chicago, IL 60603
(800) 537-2632
(312) 341-0022 (voice/TDD)
(312) 341-0295 (fax)
✉hn6177@handsnet.org

INDIANA

CAP/PADD/PAIMI/PAIR
Indiana Protection and Advocacy Services
4701 N. Keystone Ave., Ste. 222
Indianapolis, IN 46204
(800) 622-4845 (voice/TDD)
(317) 722-5555
(317) 722-5564 (fax)
✉ipas@source.isd.state.in.us

IOWA

CAP
Client Assistance Program
Division on Persons w/Disabilities
Lucas State Office Building
Des Moines, IA 50310
(800) 652-4298 (515) 281-3957
(515) 242-6119 (fax)

PADD/PAIMI/PAIR
Iowa P&A Service, Inc.
3015 Merle Hay Rd., Ste. 6
Des Moines, IA 50310
(800) 779-2502 (515) 278-2502
(515) 278-0571 TDD
(515) 278-0539
✉hn5317@handsnet.org

KANSAS

CAP
Client Assistance Program
2914 S.W. Plass Court
Topeka, KS 66611
(800) 432-2326 (785) 266-8193
(785) 266-8574 (fax)

PADD/PAIMI/PAIR
Kansas Advocacy & Protection Services
501 SouthWest Jackson, Ste. 425
Topeka, KS 66603
(913) 232-3469
(913) 232-4758 (fax)
✉jgermer@idir.net

KENTUCKY

CAP
Client Assistance Program
209 St. Clair, 5th Floor
Frankfort, KY 40601
(800) 633-6283
(502) 564-8035
✉dianehigh@uky.campus.mci.net

PADD/PAIMI/PAIR
Office for Public Advocacy
Division for P&A
100 Fair Oaks Ln., 3rd Fl
Frankfort, KY 40601
(800) 372-2988 (TDD)
(502) 564-2967
(502) 564-0848 (fax)
✉dfoy@advocate.pa.state.ky.us

LOUISIANA

CAP/PADD/PAIMI/PAIR
Advocacy Center for the Elderly and Disabled
225 Baronne, Ste. 2112
New Orleans, LA 70112-2112
(800) 960-7705
(504) 522-2337 (voice/TDD)
(504) 522-5507 (fax)
✉hn5870@handsnet.org

MAINE

CAP
CARES, Inc.
4-C Winter St.
Augusta, ME 04330
(800) 773-7055 (207) 622-7055
(207) 621-1869 (fax)
✉capsite@aol.com

PADD/PAIMI/PAIR
Maine Advocacy Services
24 Stone St., PO Box 2007
Augusta, ME 04338
(800) 452-1948 (TDD)
(207) 626-2774
(207) 621-1419 (fax)
✉hn6062@handsnet.org
✉advocate@gwi.net

MARYLAND

CAP
Client Assistance Program
Maryland Rehabilitation Center
Division of Rehabilitation Services
2301 Argonne Dr.
Baltimore, MD 21208
(800) 638-6243 (410) 554-9358
(410) 554-9362 (fax)

PADD/PAIMI/PAIR
Maryland Disability Law Center
Central Maryland Office
The Walbert Building, Ste. 204
1800 North Charles St.
Baltimore, MD 21201
(800) 233-7201 (410) 234-2791
(410) 727-6387 (voice/TDD)
(410) 234-2624 (fax)
✉hn6313@handsnet.org

MASSACHUSETTS

CAP
MA Office on Disability
Client Assistance Program
One Ashburton Pl., Room 1305
Boston, MA 02108
(617) 727-7440
(617) 727-0965 (fax)
✉blybarger@state.ma.us

PADD/PAIR
Disability Law Center, Inc.
11 Beacon St., Ste. 925
Boston, MA 02108
(617) 723-8455 (voice/TDD)
(617) 723-9125 (fax)
✉hn0473@handsnet.org

PAIMI
Center for Public Representation
22 Green St.
Northampton, MA 01060
(413) 586-6024 (voice/TDD)
(413) 586-5711 (fax)
✉hn5348@handsnet.org

MICHIGAN

CAP/PADD/PAIMI/PAIR
Michigan P&A Service
106 West Allegan, Ste. 300
Lansing, MI 48933
(800) 292-4150 (CAP only)
(517) 487-1755 (voice/TDD)
(517) 487-0827 (fax)
✉hn5293@handsnet.org
http://www.mpas.org
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MINNESOTA

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Their Community With Our Help.

✦ THE ANNANDALE STORY ✦

Annandale Village provides a natural and serene environment for adults with developmental disabilities. Annandale began through the concern of Dr. and Mrs. Maxwell Berry for the future and welfare of their child with developmental disabilities. They wanted what all parents want for their children in adulthood. . . the opportunity for the best life possible. But for the Berry's child and others with similar disabilities, future options and opportunities were very limited.

Dr. and Mrs Berry traveled extensively in the United States and abroad, studying facilities for adults with special needs. They believed that the European concept of a village community could be successfully adapted to create a desirable and beneficial alternative to institutionalization and community inclusion.

Incorporated in 1969 as a 501C(3), Annandale Village is now located on 136 acres in Suwanee, Georgia, just 30 minutes north of Atlanta. The village setting is one of natural beauty and peace among rolling hills, woodlands, pastures, orchards, vineyards, a farm, and a lake.

✦ THE SHELTERED WORKSHOP ✦

The Sheltered Workshop is a vital part of Annandale's paid vocational training program as well as an integral aspect of the Annandale concept. Workshop employment provides a source of income for many Villagers and serves as preparation for job placement outside the Annandale community. The sheltered workshop operates on a contract basis with local businesses, can perform a wide variety of jobs, and has a history of excellent quality control. References are available upon request.

✦ OUR PROGRAMS ✦

- *Paid Vocational Training and Job Placement*
- *Creative and Performing Arts*
- *Recreation/Leisure activities with skills training for Special Olympics*
- *Daily Living / Life Skills*

NNETT COUNTY
ECIAL OLYMPICS

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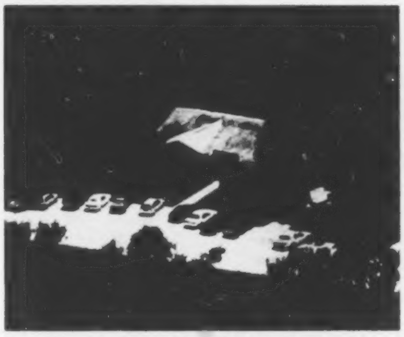
- Nutritionally balanced meals served in the Village cafeteria
- House Parenting
- Case Management
- On-campus Health Services
- Medical Monitoring
- Counseling
- Off-campus Transportation

Non-Residential Day Programming

- Appropriate services and training, including case management, are provided based on program participation.

Campus Environment



Programs Center with collegiate size, handicapped accessible gym, art gallery, sheltered workshop, and components for arts activities, educational support and recreation.

✦ ENROLLMENT ELIGIBILITY ✦

Individuals must be 18 years of age or older and ambulatory with a primary diagnosis of mental retardation, developmental disabilities, or head injured. Other diagnosis will be evaluated.

Photos by Eagle's Cry Productions, Inc.

Annandale
VILLAGE

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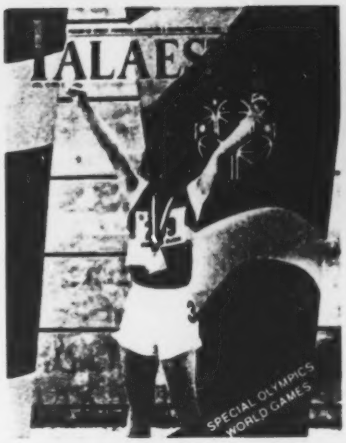

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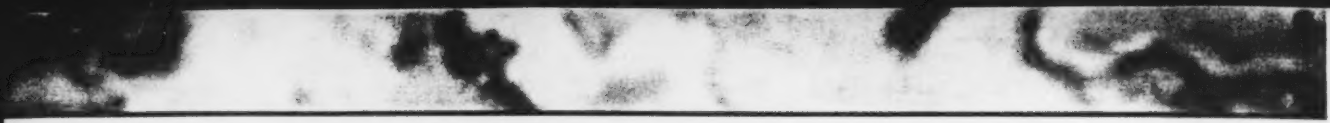

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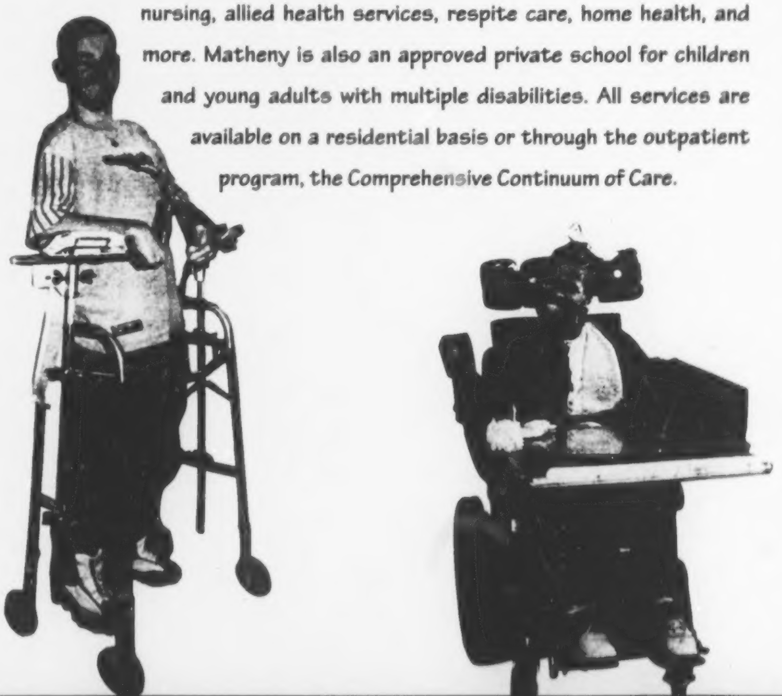

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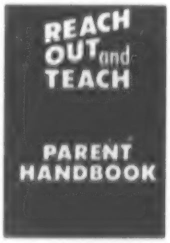
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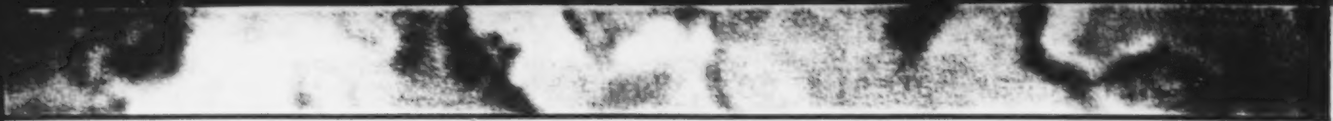

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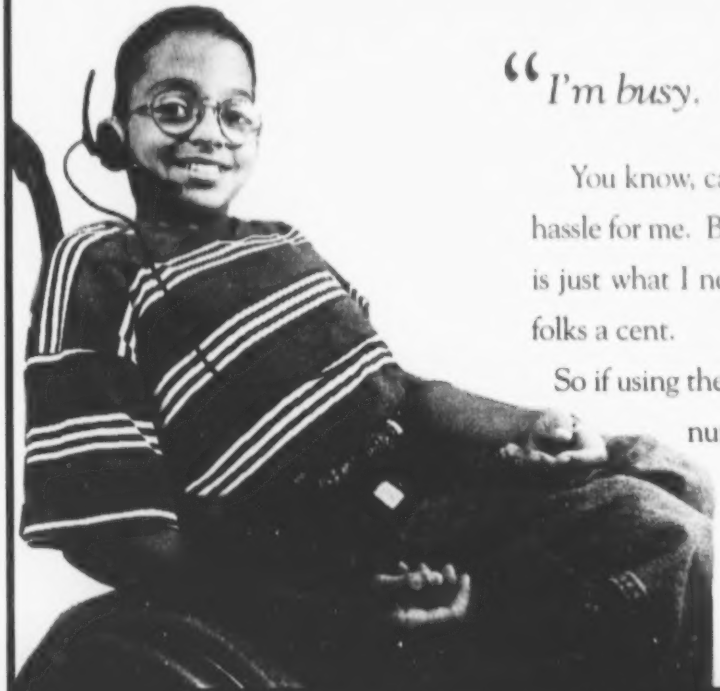

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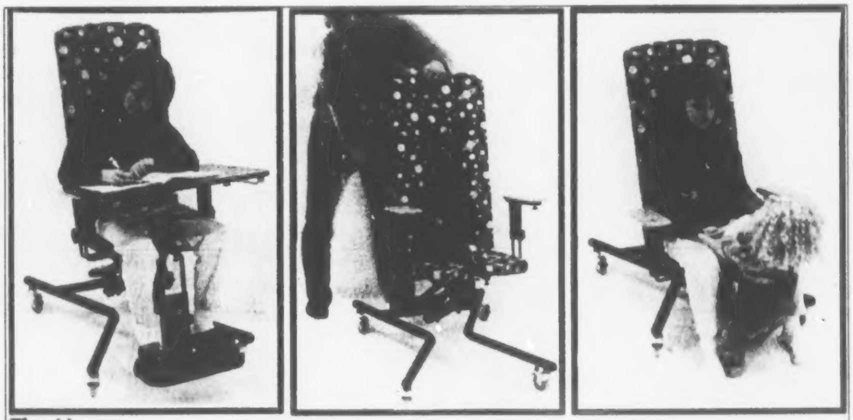

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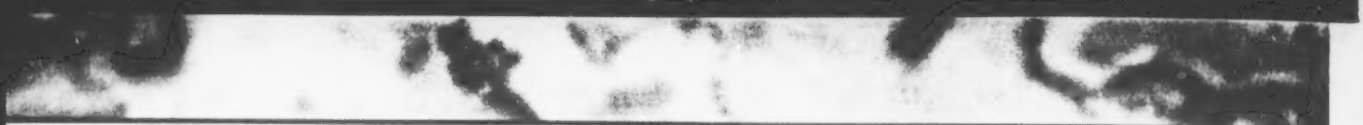

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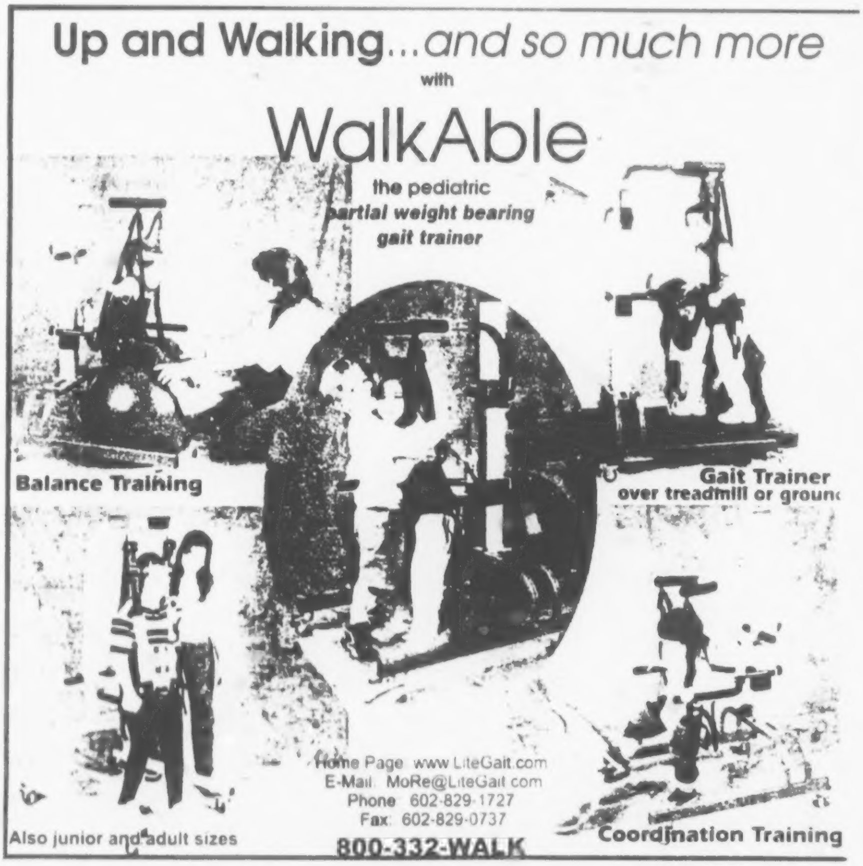

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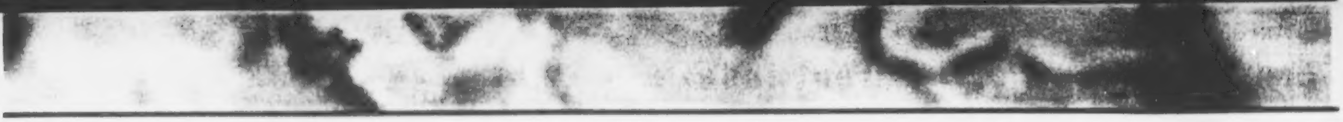

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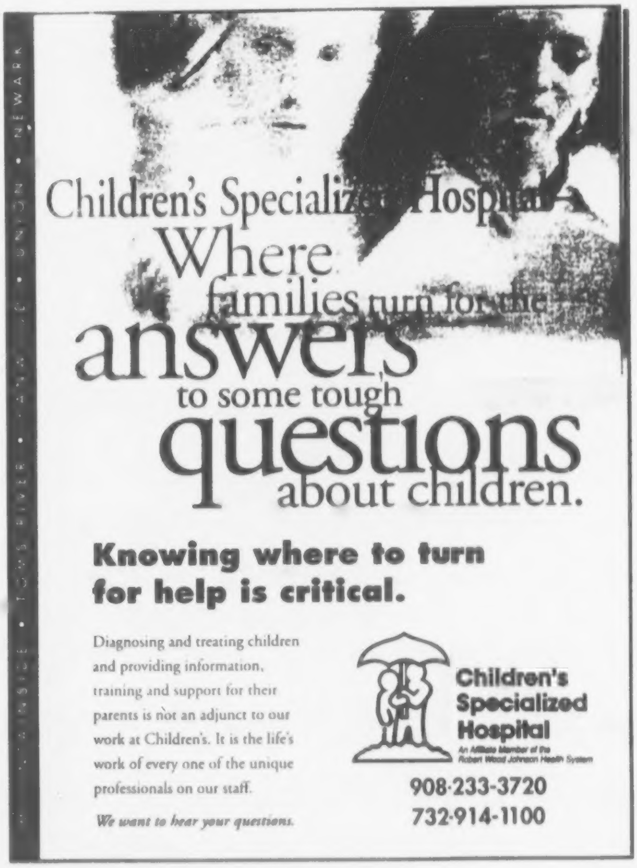
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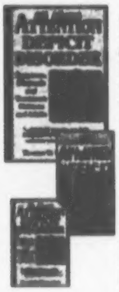

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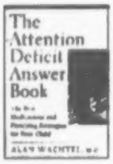

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WITH MICHAEL BOYETTE
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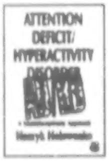

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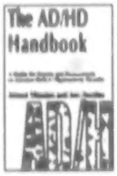

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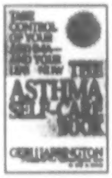

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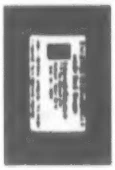

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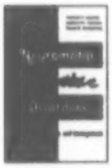

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Nature, Assessment, and Management
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KATHRYN M. YORKSTON, PH.D.,
DAVID R. BEUKELMAN, PH.D.

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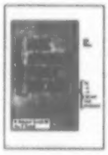

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AP02400 $24.95

The Life Planning Workbook
L.M. Russell et al
From the authors of the highly acclaimed "Planning for the Future". A hands-on guide to help parents provide for the future security and happiness of their child with a disability after their death.
AP12700 $24.95

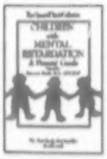
The Worst Loss
How Families Heal from the Death of a Child
Barbara D. Rosof
How do families survive the worst loss? What helps people heal? What barriers are there to healing, and what will break down those barriers?
[illegible] $14.95

Remembering With Love
Messages of Hope for the First Year of Grieving and Beyond
Elizabeth Levang, PhD.
and Sherokee Ilse
An affirming gift for those grieving the loss of a loved one, offering compassion, comfort and guidance with over three hundred short pieces written bv those who have been there.
FP0400E $11.95

What on Earth Do You Do When Someone Dies
Trevor Romain
A down to earth explanation for children about death. It offers many ways for children to cope with and understand what is happening.
FS4000E $7.95

How Do We Tell The Children
A Step By Step Guide for Helping Children Two to Teen Cope When Someone Dies
Dan Schaefer and Christine Lyons
Drawing on more than three decades of experience helping families in crises the author provides valuable information for adults to help them understand what children are capable of understanding about the loss of a loved one and how they can help them cope.
[illegible] $10.95

A Guide To Consent
AAMR
An examination of current consent issues and exploration of the policy, legal and programmatic implications of topics vital to self-determination. Written by nationally known experts who focus on critical life events of people with mental retardation and practical application of consent.
[illegible] $39.95



Children with Mental Retardation
A Parents' Guide
Edited by R.Smith, M.A., CCC-SLP
A complete and compassionate guide to everything parents need to know about raising their child and meeting their varied medical, therapeutic, and educational needs.
[illegible] $14.95

Yes! She Knows She's Here
Nicola Schaefer
A fascinating story of the life of Catherine, a woman born with severe mental retardation, and her move from her parents' house into her own home. Celebrating the 10th anniversary of her move, Cath shares the excitement and success of her efforts.
[illegible] $15.00

Before and After Zachariah
A True Story About A Family and A Different Kind of Courage
Fern Kupfer
A gripping autobiographical tale of a parent's heart wrenching decision on how to care for their newborn brain damaged son. Here we learn there are alternatives and that they, too, are honorable.
AP111GN $14.00

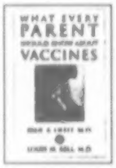
HEALTHCARE

Choosing a
Health Care
Plan

Choosing a Healthcare Plan
The Confused Consumer's Guide
Martin Gottlieb
This book is designed to help people through the confusing maze of choosing a healthcare plan. It includes professional and consumer ratings, surveys and listings of state and federal resources.
[illegible] $12.95

Your Child
and
Health
Care

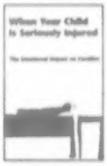
Your Child and Health Care
A "Dollars & Sense" Guide for Families with Special Needs
L.R. Rosenfeld, L.C.S.W.,Ph.D.
This resource helps parents negotiate the maze of financial assistance programs, organizations, and government services available and to seek services and assistance confidently from all sources.
PR11800 $29.00



What Every Parent Should Know About Vaccines
Paul A. Offit, MD, and Louis M. Bell, MD
An essential guide that answers the many questions regarding vaccines. With this resource parents will have the most current information available to help them make a well informed decision about their child's health and safety.
MC100HC $12.95

INJURY

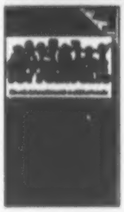
When Young Children are Injured
Families as caregivers in hospitals and at home
J. Haltiwanger M.A.,Ed M. & M. Lash, M.S.W.
A book about the family's role in caregiving when a young child is injured. Written for families with young children who have sustained debilitating injuries.
EP005ML $7.50



When Your Child is Seriously Injured
M. Lash, M.S.W.
Topics include preparing for hospital visits, reaction to loss, helping siblings, and coping.
EP005ML $4.50

Head Injury and The Family
A Life and Living Perspective
A.E. Dell Orto & P.W. Power
Focuses on how the family can adjust and survive the trauma related to head injury, as well as become a partner in the treatment, rehabilitation, and adaptation process.
[illegible] $39.95

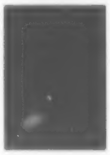
TECHNOLOGY



Oppenheim Toy Portfolio
The Best Toys, Books, Videos, Music & Software For Kids
Joanne Oppenheim
The only independent guide to children's media, this book takes the guesswork out of finding the best products for kids from infancy to age ten (10). Here are over 1,000 expert and kid-tested products that are sure to entertain as well as educate. Included are safety tips and a Basic Gear checklist for the best new and classic products your kids will love. Brand name comparisons are included
OT200ED $12.00

High Level Attention
Five exercises for remediation of attention deficits due to attention deficit disorder, traumatic brain injury, or autism. Outcome-based measurement complies with 504 therapy plans.
[illegible] $188.00

Look! Listen! and Learn Language!
Seven early intervention activities for language development. Appropriate for children with autism, PDD, Down syndrome, language delay, aphasia, or apraxia.
LT171SW $99.00



Children and Youth Assisted by Medical Technology in Educational Settings
Guidelines for Care
Second Edition
A collaborative, interactive process involving parents, students, teachers, lawyers, nurses and doctors has created this new Second Edition that reflects the reality in schools, the tension, the dilemmas, the weakness, and the strengths.
PB142ED $52.00

Enabling Technology
Disabled People, Work, and New Technology
Alan Roulstone
Addresses the role that technology will play in the reduction of attitudional and environmental barriers disabled people commonly face in the employment field. Clearly points out the need to change policy on access from a welfarist "eligibility" model to a "social rights" approach where disabled people are centrally involved in the framing, operation and review of technology access policy.
TF243GN $26.99

ANGELMAN SYNDROME

Angel Lady
Ashleigh Evans; Alice Evans
Whitney a beautiful, lively, affectionate child disabled by Angelman Syndrome is christened "Angel Lady" by her family. Unable to speak, the family through "Angel Lady Talk" devised a way to communicate. Light-hearted, optimistic and truly inspirational book.
AS100AS $12.95

Angelman Syndrome
A to Z

Angelman Syndrome From A to Z
Alice Evans; Julie Hyman
A compilation of tips, hints, and ideas on how to survive and enjoy daily life with a child with Angelman Syndrome. The collection of ideas comes from parents, teachers, siblings and care givers of people with Angelman Syndrome from around the world.
AS200AS $12.95

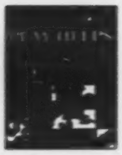
GENERAL

WHAT'S STOPPING YOU?
Living Successfully With a Disability
MARK NAGLER, PHD., AND ADAM NAGLER
This book will help walk you through critical decisions involved in: using advocacy and the law to your advantage; fighting discrimination; caring for a person with a disability; organizing your finances for long-term security and building support networks and much more.
[illegible] $25.95

PARENT PERSPECTIVE: RAISING KIDS WITH SPECIAL NEEDS
DR. PAUL WIDMAN
This video examines three families who have children with disabilities. It contains compelling interviews with both the children and the parents on what life is like when raising a child with a special health care need.
[illegible] $79.99

1-2-3 MAGIC: EFFECTIVE DISCIPLINE FOR CHILDREN 2-12
THOMAS W. PHELAN, PH.D.
A 120 minute color presentation that addresses the difficult task of child discipline with humor, keen insight and proven experience. Provides easy to follow steps for disciplining children without yelling, arguing or spanking.
[illegible] video $39.95

1-2-3 MAGIC: EFFECTIVE DISCIPLINE FOR CHILDREN 2-12
New Revised 2nd Edition
THOMAS W. PHELAN, PH.D.
A how-to text designed to help adults learn how to handle difficult behavior, encourage good behavior, and manage the inevitable sidetrack of testing and manipulation - all in a manner that is fair, perfectly clear and not abusive.
[illegible] book $12.95
[illegible] audiotape $24.95

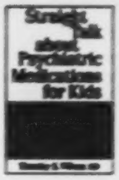


PLAY HELPS
Toys and Activities for Children with Special Needs
Fourth Edition
ROMA LEAR
Beginning in 1977 as "The Orange Book", this revised edition includes a compilation of more toys and games arranged under the five senses. Each chapter begins with a contents list. Includes ideas for toys that children can make.
[illegible] $37.50

DISABILITY DISCOURSE
Disability, Human Rights and Society
MAIRIAN CORKER AND SALLY FRENCH
A look at the multidimensional and multifunctional nature of disability language in an attempt to further improve our understanding of disability and establish it as a serious topic of study; one in which the latest research findings and ideas can be seriously influential.
[illegible] $29.95

Sleep Better!

SLEEP BETTER
A Guide For Improving Sleep for Children With Special Needs
V. MARK DURAND, PHD.
This text begins with a discussion of sleep followed by a description of a range of sleep problems and includes a step by step interview that will help you identify the type of problems being encountered. Includes teatment options covering bedwetting, sleep walking, insomnia and much more.
[illegible] $21.95



STRAIGHT TALK ABOUT PSYCHIATRIC MEDICATIONS FOR KIDS
From a Leading Authority, An Essential Guide
TIMOTHY E. WILENS, MD
If your child is among the estimated 12 to 22 percent of American kids who suffer from psychiatric disorders, this text may be helpful to you as you face the tough questions of: Should we use medication? How can I assure the best possible treatment with the least possible risk? How do I monitor my child's care? Includes resource list for additional information.
[illegible] $14.95

RESEARCHING DISABILITY ISSUES
MICHELLE MOORE, SARAH BEAZLEY, AND JUNE MAELZER
Designed to meet a growing need for clear illustrations of how to carry out research which seeks to explore disability issues. Demonstrates value of a critical attention to social, rather than medical starting points for researching disability. Includes substantive examples of the dilemas which face researchers.
[illegible] $26.99

AFTER YOUR CHILD'S DIAGNOSIS
A Practical Guide for Families Raising Children With Disabilities
CATHY LYNN BINSTOCK
This book offers practical assistance in the way of resources, references, and options available when seeking treatments after a child has been diagnosed. Included are both positive and negative experiences to help one anticipate and cope.
[illegible] $21.95

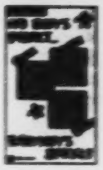
EXTRAORDINARY KIDS
Nurturing and Championing Your Child With Special Needs
JONI EARECKSON TADA
Filled with the personal experiences and ancedotes of many parents who have raised children with special healthcare needs. This book provides parents with the hope, inspiration, and insight they need to capture the unique joy of their child.
[illegible] $18.99

UNDERSTANDING AND SUPPORTING CHILDREN WITH EMOTIONAL AND BEHAVIOURAL DIFFICULTIES
PAUL COOPER
A close examination of the nature of emotional and behavioral disorders, their potential causes, and discussion of the issues that can arise for professionals involved in their assessment. Also includes exploration of the future of the treatment of emotional behavioral difficulties.
[illegible] $68.95

JUST FRIENDS
Disability Issues Series
Just Friends looks at three long term friendships between people with and without developmental disabilities. It is a narrative on the true nature of friendship, and is a terrific tool in the classroom. Time: 22 minutes
[illegible] Video $49.00

Happy Family

BUILD A HAPPY FAMILY
A Positive Parenting Tool Kit on "How to be the Parent You Want to be When You Just Don't Have the Time"
FRANK J. DOBERMAN, PH.D.
This book introduces the twelve basic skills of positive parenting and also show parents how to find the time to use these tools while having the energy to become the parents they want to be, with happy, healthy and thoughtful children.
[illegible] Book $25.20
[illegible] Video $20.00
[illegible] Both $29.95



NOBODY'S PERFECT, EVERYBODY'S SPECIAL
A video and teacher's manual designed to identify and acknowledge special health conditions, increase awareness and acceptance, demonstrate respect for others and teach the value of friendship and community. The story evolves around the Head Over Heels Body Shop, where the mechanic, Jack, and his three friends attempt to fix the misconceptions that many people have about people with disabilities. Close captioned.
[illegible] $89.99

IT'S ALL PART OF THE JOB
Social Skills For Success At Work
This video features real life workers with developmental diabilities, and extensive interviews with their employers. It attempts to teach job skills that everyone can use. Focuses on the major rule of thumb in the jobplace: Ask, Listen and Learn. Excellent teaching tool lasting 21 minutes.
[illegible] Video $59.00

UNCOMMON FATHERS
Reflections on Raising a Child with a Disability
EDITED BY D.J. MEYER
A compelling collection of essays by fathers who were asked to reflect and write about the life-altering experiences of having a child with a disability.
[illegible] $14.95

STEPS TO INDEPENDENCE

STEPS TO INDEPENDENCE
Teaching Everyday Skills to Children With Special Needs
Third Edition
BRUCE L. BAKER & ALAN J. BRIGHTMAN
A step by step guide to help parents teach essential life skills to their children. Includes behavioral problems management, toilet training, home care skills, chores and much more.
[illegible] $23.00

DICTIONARY OF DEVELOPMENTAL DISABILITIES TERMINOLOGY
PASQUALE J. ACCARDO & BARBARA Y. WHITMAN
This valuable dictionary is an essential tool for anyone involved in caring for a child with developmental disabilities. More than 3000 terms with thorough and easy to understand definitions including Anomia, Down syndrome, Cerebral Palsy, and much more.
[illegible] $36.95

YES YOU CAN!
A Guide for Parents of Children with Disabilities
MARK NAGLER, PH.D.
Parents and caregivers are provided with advice and support for maintaining the quality of family, personal and social life while maximizing the rehabilitative potential of the child with special needs.
[illegible] $21.95

CHILDREN WITH DISABILITIES
A Medical Primer
Fourth Edition
M.L. BATSHAW, M.D. & Y.M. PERRET, M.A.
For parents and professionals. Over 200 detailed illustrations, an extensive glossary, and a section on syndromes.
EXCEPTIONAL PARENT REVIEWED THE BOOK IN THE 11/97 ISSUE.
[illegible] $58.00

grief dancers

GRIEF DANCERS: A JOURNEY INTO THE DEPTHS OF THE SOUL
SUSAN ZIMMERMAN
A mother's story of achieving unconditional love and acceptance of her handicapped child for *who* she is, and not *what* she is.
EXCEPTIONAL PARENT REVIEWED THE BOOK IN THE 5/98 ISSUE.
[illegible] $14.95

In Time and With Love

Caring for the Special Needs Baby

Marilyn Segal, Ph.D.

For families and caregivers of preterm and handicapped children in their first three years. More than 100 tips on adjusting and coping, nursing, dressing, social skills, games and activities, discipline, decision making, and much more.

[illegible] $25.95

Potty Learning For Children Who Experience Delays

S.R. Hays, M.S. R.N., C.R.R.N.

This video presents a unique developmental approach to supporting the child in learning independence in the management of "bathroom" skills.

[illegible] $29.95

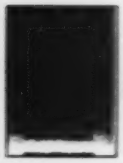
The Explosive Child

A New Approach for Understanding and Parenting Easily Frustrated, "Chronically Inflexible" Children

Ross W. Greene, Ph.D.

Practical comprehensive approach aimed at decreasing adversarial interactions between parents and children, reducing family hostility and improving children's capacities for flexibility, frustration tolerance, communication and self-regulation.

[illegible] $24.00



Journeys

Finding Life's Way In Spite of Obstacles

Albion R. Evans, Carl W. Morris, and Curtis C. Garfield

A book that should be read and re-read as it is a collection of wonder-filled stories of courage and resilience that are both inspiring and humbling from people who are physically challenged. It exemplifies how those who are challenged do not need pity, sympathy or even our compassion; but rather they deserve respect.

[illegible] $22.95

Disability Politics and Community Care

Mark Priestley

Addresses the relationship between the politics of disability and community care policies currently under law. It encourages both health and welfare professionals and policy makers to start working much more closely with disabled people.

[illegible] $24.95

SPECIAL EDUCATION

Cooperative Learning and Strategies for Inclusion

Celebrating Diversity In The Classroom

JoAnne W. Putnam

This guide shows educators how to make group learning strategies work in their classrooms. There are chapters written by a distinguished array of professionals who reveal the real educational benefit of a cooperative learning environment.

[illegible] $25.95

You, Your Child, and "Special" Education

A Guide to Making the System Work

B.C. Cutler, Ed.D.

Shows parents how to obtain the educational services their child rightfully deserves.

[illegible] $24.00

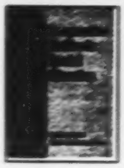
The History of Special Education

From Isolation to Integration

Margaret Winzer

A look at how special education came about, and the struggles that those with special needs faced when trying to get an education without it.

[illegible] $55.95



Comparative Studies In Special Education

Kas Mazurek and Margaret A. Winzer

Written by distinguished special educators from around the world, this text is a series of reports and analyses that focus on: the current state of special education in selected nations, major issues and controversies in the field within those nations, and emerging and future trends.

[illegible] $55.95

Negotiating the Special Education Maze

A Guide for Parents and Teachers

W. Anderson, S. Chitwood, & D. Hayden

An easy to understand, step-by-step guide for parents of children with special needs and the teachers and professionals who assist them.

[illegible] English $26.95

[illegible] Spanish $26.95

The Complete IEP Guide

How to Advocate for Your Special ED Child

Lawrence M. Siegel

A comprehensive step by step guide through the entire IEP process that provides encouragement to the reader as it takes a complicated process and makes it easier to understand. Provides instructions, suggestions, strategies, resources, forms and much more.

[illegible] 24.95

The Prospector Goal Mine #2

Donald Cahill and Maureen Cahill

Written in parent-friendly language; designed to help parents and educators through the Individualized Educational Plan (IEP). Segmented into 26 educational needs areas. Includes more than 5000 examples of good goals and objectives and their application.

[illegible] $38.95

A New IDEA For Special Education: Understanding The System And The New Law A Guide for Parents. A Tool for Educators

Through examination of IDEA provides insight as to role of parent and rights of children. Topics include: the new law; the referral process; child evaluation; creation of IEP; placement and related services; transition preparation; and more.

[illegible] $49.95

Inclusion in Secondary Schools

Bold Initiatives Challenging Change

Daniel D. Sage, PhD.

A total of 23 authors contributed to the eight chapters that describe a variety of experiences with inclusive efforts at the secondary level. The text provides a chronicle of real events, places, and persons; an inside look at attempts and successes that challenged the status quo of special education philosophy and practice.

[illegible] $29.95

Inclusion: An Essential Guide For The Paraprofessional

A Practical Reference Tool for All Paraprofessionals Working in Inclusionary Settings

Peggy A. Hammeken

Partnership is a key to inclusive education and the paraprofessional is an indispensible member of the team. This resource contains more than 300 easy-to-use strategies for use in the classroom and school environment. Many reproducible forms.

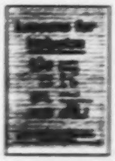
[illegible] $21.95

How To Write An IEP

John Arena

Parents, teachers, administrators and others involved in IEP preparation and implementation will profit from this brief, easy-to-use, handbook. This text will serve as an invaluable reference for making sure all factors of consequence are given the consideration they require.

[illegible] $19.95



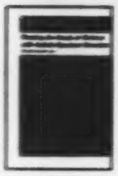
Lessons For Inclusion

O'Brien, and Forest with Snow, Pearpoint and Hasbury

An excellent book that relates all the aspects of inclusion and gives a range of activities to help children adapt to their new surroundings. It helps make a different situation easy to adapt to. Spiral Bound

[illegible] $22.00

AUTISM



Meeting the Needs of Children With Autistic Spectrum Disorder

Rita Jordan and Glenys Jones

A terrific tool for anyone teaching children with autistic spectrum disorders for the first time in a mainstream setting. It uses a case study approach to identify the meaning behind pupils actions and reactions.

[illegible] $27.95

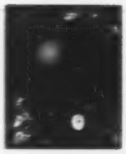
Teaching Children with Autism

Strategies for Initiating Positive Interactions and Improving Learning Opportunities

Robert L. Koegel & Lynn Kern Koegel

Provides a useful conceptual and practical guide for teaching children with autism in a way to maximize their developmental potential. Limited to behavioral interventions that have been scientifically documented to be effective and will result in socially significant and durable behavior change.

[illegible] $35.00



Andy and His Yellow Frisbee

By Mary Thompson

Introduces young readers of (elementary school age) to autism. Illustrated with vivid watercolors and signs to be shared with friends, siblings and classmates so they may get a better understanding of a disability to which they may have had little exposure.

[illegible] $14.95

SIBLINGS

It Isn't Fair!

Siblings of Children with Disabilities

Edited by S.D. Klein & M.J. Schleifer

Features chapters by parents, siblings and professionals.

[illegible] $18.95

By Exceptional Parent's Co-Founder

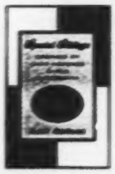
Views from our Shoes

Growing up with a brother or sister with special needs

Donald Meyer

A new book for children by children who share their experience as the brother or sister of someone with special needs— The good and bad aspects, as well as many thoughtful observations. May be useful to educators to supplement their inclusion programs.

[illegible] $14.95



Special Siblings

Growing Up With Someone With A Disability

Mary McHugh

The real life story of a woman who raised her disabled brother after their mother's death. Her insights into the positive impact that her brother had on her life and development are simply inspirational.

[illegible] $23.95

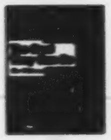
"OVER A QUARTER CENTURY OF CARING"

LEARNING DISABILITIES, LITERACY, AND ADULT EDUCATION
SUSAN A. VOGEL AND STEPHEN REDER
A sharing of cutting-edge developments and information from specialists in their fields about LD, literacy, and adult education, an often overlooked special needs area. Includes how and when to screen and methods for teaching adults who have LD.
[illegible] $49.95

HELPING PEOPLE WITH A LEARNING DISABILITY EXPLORE RELATIONSHIPS
EVE AND NEIL JACKSON
This book focuses on the nature of relationships by examining a house inhabited by five people with learning disabilities. There are several subplots that deal with love, grief, and simple friendship.
[illegible] $24.95

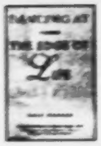
UNCOMMON GIFTS
Transforming Learning Disabilities into Blessings
JAMES S. EVANS
An autobiography about a man's triumphant battle against a variety of learning disabilities and the social pressures that come with them from birth through adulthood including a happy marriage.
[illegible] $22.99

INTERVENTIONS FOR STUDENTS WITH LEARNING DISABILITIES
A Meta-Analysis of Treatment Outcomes
H. LEE SWANSON WITH MAUREEN HOSKYN AND CAROLE LEE
A scientific study of different treatment methods used to improve the skills of learning disabled people.
[illegible] $25.00



THE BEST THEY CAN BE
The Wildwood Story
VIRGINIA BORSICK AND KATHERINE COHEN
The true stories of four families with children who have learning disabilities or neurologically based developmental disabilities. It also chronicles the history and development of Wildwood, a group organization devoted to helping those with learning disabilities.
[illegible] $35.00

BRAIN INJURY



DANCING AT THE EDGE OF LIFE
A Memoir
GALE WARNER
The author, an exceptional, sensitive and passionate soul, compiled an autobiography about her battle against cancer and provides a moving and compelling testament to the human spirit.
[illegible] $22.95

THE SHORTEST DISTANCE
The Pursuit of Independence for Individuals with Acquired Brain Injury
BRIAN T. MCMAHON, PH.D. AND RANDALL W. EVANS, PH.D.
One company's inside story of what can be achieved if you are dedicated to the ongoing and relentless pursuit of quality in the alternate site specialty health care industry.
[illegible] $45.00

LIFE CARE PLANNING FOR THE BRAIN DAMAGED BABY
A Step by Step Guide
JULIE A. KITCHEN, L. STUART CODY AND PAUL M. DEUTSCH
An innovative and comprehensive multidisciplinary approach which systematically documents the needs of a catastrophically injured individual and projects the costs of needed goods and services. Step by step format includes valuable references.
[illegible] $25.00

continued on page 193

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A Book for Brain Tumor Patients and Their Families
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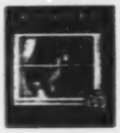

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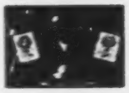

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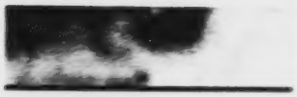

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Exceptional Parent

January 2000

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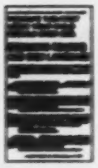
HEARING IMPAIRED

Sign Songs
Fun Songs to Sign and Sing
National Theatre of the Deaf
A video that is designed for both children and parents alike, offering a fun way to learn to sign and communicate with those who are hearing impaired.
Video 29 minutes/Color
[illegible] $19.98

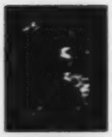
Deaf and Disabled Or Deafness Disabled?
Marian Corker
Using a multidisciplinary, postmodernist approach in the search for an inclusive framework for understanding deafness and disability the text exposes the essentialism inherent in existing social, political and service frameworks which confuses issues of needs and rights and contribute to the creation and reinforcement of the power imbalances at the heart of disability oppression.
[illegible] $25.95

The Words They Need
Welcoming Children Who Are Deaf And Hard Of Hearing To Literacy
Jessica Stelling
An in depth examination of the relationship between acquisition of vocabulary, grammar and reading within the needs of the child who has hearing impairments.
[illegible] $29.50



Beginning Reading and Sign Language
A video for those who wish to have their children learn sign. It is user friendly to both the hearing impaired and those who wish to learn sign as a form of communication with those who are hearing impaired.
[illegible] $19.99

I'm Deaf and It's Okay
L. Aseltine, E. Mueller & N. Tait,
Pictures by H. Cogancherry
How this little boy copes with the frustrations of deafness at play and at home.
[illegible] $14.95



Dina the Deaf Dinosaur
Carole Addabbo/Illustrated By Valentine
Not only a terrific guide to the language of Sign, it is a very effective example of how important communication is.
[illegible] $19.95

Chris Gets Ear Tubes
Betty Pace Illustrated by Kathryn Hutton
An explanation of what happens before, during, and after the surgery in language a child can understand. It takes away the child's natural fear of the unknown
[illegible] $9.95

Moses Goes To A Concert
Isaac Millman
A story about a hearing impaired going to a concert for the first time and his experiences at this special event. The book is written in sign and english.
[illegible] $16.00

Sign and ABC's
A New Way To Play
National Theatre of the Deaf
A fun video that teaches adults and children how to sign the alphabet, and offers an introduction to spelling.
Color/ 50 minutes
[illegible] Video $14.98

The Silent Garden
Raising your Deaf Child
Second Edition
Paul W. Ogden
An up to date reference comprising all the bits and pieces of advice, encouragement and hard data that parents might need in order to make decisions that will enable their children to grow into strong, healthy and productive members of society.
[illegible] $25.95

Legal Rights
The Guide For Deaf And Hard Of Hearing People
National Center For Law And Deafness
This fourth edition contains complete information on the Americans with Disabilities Act, the Television Decoder Circuitry Act, and full updates on all other laws and legislation that affect deaf and hard of hearing people. Excellent guide for compliance.
[illegible] $19.95

A Button in Her Ear
Ada B. Litchfield
Pictures: Eleanor Mill
Approximately 7% of school children have some degree of hearing loss. Story reinforces a child's healthy attitude toward use of a hearing aid. For children in similar circumstances this story has special meaning and sets the stage for new understanding.
[illegible] $14.95

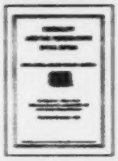
Helen Keller Public Speaker
Sightless But Seen, Deaf But Heard
Lois J. Einhorn
Helen Keller was an uplifting orator who spoke from a unique vantage point for the cause of social improvement. This is a collection and analysis of some of her finest speeches and presentations.
[illegible] $55.00

My Signing Book of Numbers
Patricia Bellan Gillen
This full-color picture book helps children learn their numbers in sign language. Each two-page spread has the appropriate number of things or creatures for the numbers 0 to 20. Signs for 30, 40, etc. to 100 and instructions on "how to" are included.
[illegible] $14.95

SPINA BIFIDA

Answering Your Questions About Spina Bifida
A Guide from the Spina Bifida Program Department of General Pediatrics
Edited by C. Shaer
Contains information to help understand basic medical, educational, and social issues of children and adults with spina bifida.
[illegible]-english $6.95
[illegible]-spanish $6.95
Available in Spanish

Medical Facts About Spina Bifida
C.T. Dipoli, M.D. & S.L. Kinsman, M.D.
Information to answer your basic questions about spina bifida.
[illegible] $4.00



Sexuality And The Person With Spina Bifida
Spina Bifida Association of America
It is important to understand the impact that spina bifida has on sexuality. It is more important that the potential for healthy expression that does exist for persons with spina bifida be understood and education be made available for them and their families.
[illegible] $9.95

VISUALLY IMPAIRED

Can't Your Child See?
A Guide for Parents of Visually Impaired Children
E. Scott, H. Jan & R. Freeman
Practical guidelines for helping visually impaired children reach their full potential.
[illegible] $28.00

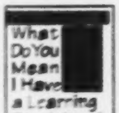
Children with Visual Impairments
A Parents' Guide
Edited: M. Cay Holbrook, Ph.D.
Designed to help parents get a handle on common types of concerns. Written by a team of professionals and parents, each of whom is an expert on a different aspect of caring for children with visual impairments.
[illegible] $26.95

LEARNING DISABILITIES

Planning For Success
The College Application Process for Students With Learning Disabilities
The college admission process can be a confusing and overwhelming experience for students with learning disabilities and their families. This comprehensive video enables you to see the college application process from the very beginning. It shows early planning, college visits, the essays, and how to choose the best school for you.
[illegible] $49.99

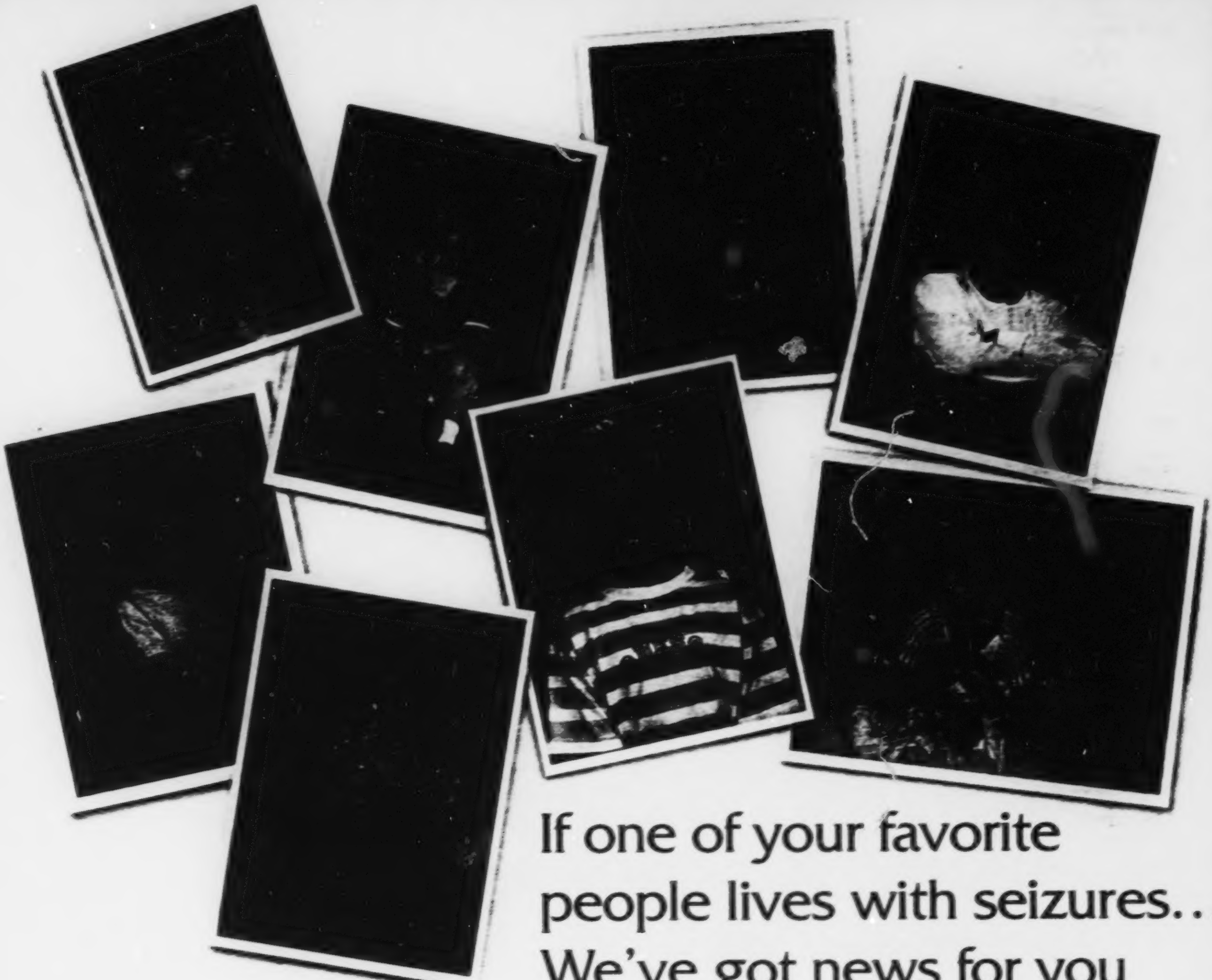
Special Talents, Special Needs
Drama for People With Learning Disabilities
Ian McCurrach and Barbara Darnley
A handbook for teachers and facilitators working with learning disabled people who are interested in creative expression through drama. A step-by-step guide beginning with finding an appropriate setting and assessing the group and progressing through five parts and thirty different sessions to conclude with the planning of a showing or performance.
[illegible] $29.95

I Wish I Could Fly Like A Bird
Audio Tape and Book
Katherine Denison
Children who have been taunted for being different, who have ever felt embarrassed socially, who have resorted to bravado in the face to shame will understand Chic L Dee, a boy bird who discovers his talents; trusts his intuition; and finds his own way.
Exceptional Parent reviewed the book in the 3/98 issue.
[illegible] $17.95



What Do You Mean I Have A Learning Disability?
Kathleen M. Dwyer
Photographs by Barbara Beirne
For children who are learning disabled and their families and friends, this inspiring book offers encouragement and support in a shared effort. The story of a ten year old who was not diagnosed until a teacher discovered the problem.
[illegible] $14.95

The Experts Speak
Parenting the Child With Learning Disabilities
Teresa A. Citro
A clear, comprehensive, and direct collection of writings by professionals in the field of learning disabilities in their area of concentration. Whether it is teaching, parenting, or socialization there are stories on it here.
[illegible] $18.99



If one of your favorite people lives with seizures…
We've got news for you

News about treatment. Research. Camping opportunities. School programs and educational materials. News about legal issues. A cheerful publication just for kids. Tips on safer living. Tips for parents. Reports on progress in the fight against prejudice and ignorance. It's all in *EpilepsyUSA*, our news publication for members. Join the Epilepsy Foundation and get your copy of *EpilepsyUSA* and *KidsNews.*

Because every day brings new developments in the fight against seizure disorders.

EPILEPSY
FOUNDATION
Leading the Fight Against Seizure Disorders

MEMBERSHIP APPLICATION

Send to: Epilepsy Foundation Membership
4351 Garden City Drive, Landover, MD 20785

Enclosed is my check for $25 for a one year membership, which includes a year's subscription to *EpilepsyUSA.*

Name ______________________________

Address ______________________________

City, State, Zip ______________________________

DAEPZZT

Product & Services Directory

AQUATICS

Aquatic Access, Inc.
swimming pool/spa/boat/dock lifts
www.AquaticAccess.com
(800) 325-LIFT
Louisville, KY USA

ASSISTIVE TECHNOLOGY

AbleNet, Inc.
1081 Tenth Avenue S.E.
Minneapolis, MN 55414
(800) 322-0956
Fax: (612) 379-9143
www.ablenetinc.com 20

AMDI
31 Watermill Lane
Great Neck, NY 11021
(516) 466-2288
Fax (516) 466-2435

Assistive Technology Program at Children's Hospital
Evaluation and training on daily living aids, communication devices, customized seating, etc.
2924 Brook Road
Richmond, Virginia 23220
Information & Referrals
(804) 228-5818
http://www.childrenshosp-richmond.org
Circle # 34
See our ad on page 112

Assistive Technology, Inc.
7 Wells Avenue
Newton, MA 02459
(617) 641-9000
Fax: (617) 641-9191
www.assistivetech.com
Circle # 24
See our ad on page 24

Assistive Technology, Inc.
1415 N. Eagle Street
Naperville, IL 60563
(800) 244-4906
Fax: (630) 527-0111
✉dond@assistivetechnologies.com
Assistive technology assessments, computers, training for vision, hearing, speech, mobility and learning impairments, power AT all day long from wheelchair battery using our MACH-1
Circle # 24
See our ad on page 24

Barrier Free Lifts®, Inc.
9230 Prince William Street
Manassas, VA 20110
(800) 582-8732
Fax: (703) 361-7861
http://bfl-inc.com
Circle # 25
See our ad on page 68

BigKeys Keyboard
P.O. Box 1888
Huntersville, NC 28078
(800) 249-5397
Fax: (704) 875-8936
http://www.bigkeys.com
BigKeys Plus is a serious alternative keyboard with 1" keys, for kids and adults. Easy to use ABC or standard QWERTY formats. Both formats available in multi colored or white keys. No special software required.

DynaVox Systems, Inc.
2100 Wharton Street, Suite 400
Pittsburgh, PA 15203
(888) 697-7332
Fax (412) 381-5241
www.dynavoxsys.com
Circle # 49
See our ad on page 99

IBM
11400 Burnett Road
Suite 9171
Austin, TX 78758
(800) 426-4832
Voice: (800) 426-4833
TTY: (800) 426-2255
www.ibm.com/sns
Circle # 67
See our ad on page 3

IntelliTools, Inc.
55 Leveroni Court, Suite 9
Novato, CA 94949
(800) 899-6687
Fax: (415) 382-5950
www.intellitools.com
Customizable curriculum software to meet your child's needs.
Circle # 69
See our ad on page 86

Kaplan Companies Inc.
1310 Lewisville-Clemmons Road
Lewisville, NC 27023
(800) 334-2014
www.kaplanco.com
Circle # 72
See our ad on page 175

Matheny School and Hospital
Box 339 Main Street
Peapack, NJ 07977
(908) 234-0011
Fax: (908) 234-2137
www.matheny.org
✉info@matheny.org
Circle # 86
See our ad on page 165

Ocean Hyperbaric Center
4001 N. Ocean Boulevard
Lauderdale-By-The-Sea, FL 33308
(954) 771-4000
Fax: (954) 776-0670 20
Circle # 97
See our ad on page 38

RJ Cooper & Associates
24843 Del Prado # 283
Dana Point, CA 92629
(800) RJCOOPER 20
Fax: (949) 240-9785
www.rjcooper.com
Circle # 113
See our ad on page 27

Seiko Instruments
2990 West Lomita Boulevard
Torrance, CA 90505
Toll Free: (877) 344-4040
www.readingpen.com
✉cpd.info@seiko-la.com
Circle # 116
See our ad on page 27

Smart Input, Inc.
1460 Pittman Avenue
Sparks, NV 89431
(800) 366-8323
Fax (775) 358-9675
www.smartinput.com
Portable word processing keyboard with features for the disabled.
Circle # 118
See our ad on page 95

AUGMENTATIVE COMMUNICATIONS EQUIPMENT

AMDI
31 Watermill Lane
Great Neck, NY 11021
(516) 466-2288
Fax (516) 466-2435
Circle # 138
See our ad on page 79

Assistive Technology, Inc.
7 Wells Avenue
Newton, MA 02459
(617) 641-9000
Fax: (617) 641-9191
www.assistivetech.com
Circle # 24
See our ad on page 24

Communication Aids for Children & Adults
6625 N. Sidney Place
Milwaukee, WI 53209
(414) 352-5678
Fax: (414) 352-5679
www.communicationaids.com

Communication Devices, Inc.
421Coeur d'Alene Avenue, Suite 5
Coeur d'Alene, ID 83814
(208) 765-1259 or (800) 604-5559
Fax: (208) 765-1529
✉hollycom@nidlink.com
www.comdevices.com

DynaVox Systems, Inc.
2100 Wharton Street, Suite 400
Pittsburgh, PA 15203
(888) 697-7332
Fax: (412) 381-5241
www.dynavoxsys.com
Circle # 49
See our ad on page 99

Kaplan Companies Inc.
1310 Lewisville-Clemmons Road
Lewisville, NC 27023
(800) 334-2014
www.kaplanco.com
Circle # 72
See our ad on page 175

LC Technologies Eyegaze Systems
9455 Silver King Court
Fairfax, VA 22031
(800) 393-4293
Fax: (703) 385-7137
www.eyegaze.com
Eyegaze System lets your child communicate with his or her eyes. Speech output, typing, environmental control, and access to complete

Prentke Romich Company
1022 Heyl Road
Wooster, OH 44691
Voice: (800) 262-1933
Fax: (330) 263-4829
e-mail: info@prentrom
www.prentrom.com
Circle # 106
See our ad on pages 72-73

Smart Input, Inc.
1460 Pittman Avenue
Sparks, NV 89431
(800) 366-8323
Fax: (775) 358-9675
www.smartinput.com
Portable word processing keyboard with features for the disabled.
Circle # 118
See our ad on page 95

The Great Talking Box Company
2245A Fortune Drive
San Jose, CA 95131
(408) 456-0151
Fax: (408) 456-0134
www.gtb-sym.com
GTB is dedicated to providing affordable augmentative communication devices that are flexible, accessible, and which seamlessly connect users with the world. Featuring the EasyTalk, Alltalk2, and the E-talk, we have all levels of devices that are utilized worldwide.
Circle # 205
See our ad on page 95

AUGMENTATIVE EVALUATION

Kaplan Companies Inc.
1310 Lewisville-Clemmons Road
Lewisville, NC 27023
(800) 334-2014
www.kaplanco.com
Circle # 72
See our ad on page 175

BATHROOM EQUIPMENT

Barrier Free Lifts®, Inc.
9230 Prince William Street
Manassas, VA 20110
http://bfl-inc.com
Circle # 25
See our ad on page 68

Columbia Medical Mfg. Corp.
P.O. Box 633
Pacific Palisades, CA 90272
(800) 454-6612
Fax: (310) 305-1718
www.columbiamedical.com
Circle # 37
See our ad on page 83

Duralife, Inc.
195 Phillips Park Drive
S. Williamsport, PA 17702
(570) 323-9743
Fax: (570) 323-9762
www.duralife-usa.com
Circle # 47
See our ad on page 126

James Leckey Design, Inc.
360 Merrimack Street, Riverwalk #9
Lawrence, MA 01843
(800) 532-5390
Fax: (978) 691-5230
www.leckey.com

Maddak, Inc.
6 Industrial Road
Pequannock, NJ 07440
(973) 628-7600
Fax: (973) 305-0841
✉ custservice@maddak.com 20
www.maddak.com
Circle # 81
See our ad on page 129

Otto Bock Rehab
3000 Xenium Lane
Minneapolis, MN 55441
(800) 328-4058
www.ottobockus.com
Circle # 98
See our ad on page 47

Snug Seat, Inc.
12801 E. Independence Blvd.
Stallings, NC 28105
(800) 336-7684
Fax: (704) 882-0751
www.snugseat.com
Circle # 120
See our ad on page 85

BEDDING

Hard Manufacturing
230 Grider Street
Buffalo, NY 14215
(800) USE-HARD
Fax: (716) 896-2579
Our "Age Appropriate" beds and cribs accommodate your child with the safety and convenience you would expect from the #1 mfg.
Circle # 63
See our ad on page 16

Hertz Supply Co. Inc.
4670 Schantz Road, Suite A
Allentown, PA 18104
(800) 321-4240
Fax: (610) 366-1808
www.hertzsupply.com
"The health care bed in disguise" that's the Volker style.
Circle # 65
See our ad on page 84

Vail Products
235 First Street
Toledo, OH 43605
(800) 235-VAIL (8245)
Fax (419) 698-1174
www.vailbed.com
Circle # 133
See our ad on Cover 4

BICYCLES

CycleTote Corporation
Bicycle Trailer/Jogger/Stroller
Fort Collins, CO 80524
(800) 747-2407
Fax: (970) 482-2402
www.cycletote.com
Circle # 43
See our ad on page 40

Haverich Ortho-Sport
67 Emerald Street
Keene, NH 03431
(603) 358-0438
Fax: (603) 358-0453
✉ Josh-nh@top.monad.net 20
Circle # 64
See our ad on page 176

CLOTHES

Adrian's Closet
800-831-2577
Wheeling Clothes
www.adrianscloset.com 20

MJ Markell Shoe Com.
504 Saw Mill River Road
Yonkers, NY 10702
(914) 963-2258
Fax: (914) 963-9293
http://www.markellshoe.com
Circle # 80
See our ad on page 97

Plum Enterprises, Inc.
Exquisite Ergonomic ProtectiveWear™
500 Freedom View Lane
Post Office Box 85
Valley Forge, PA 19481
(610) 783-7377
Fax: (610) 783-7577
Toll Free: 1-800-321-PLUM
www.plument.com
Circle # 104
See our ad on page 80

COMPUTER HARDWARE & ACCESSORIES

Assistive Technology, Inc.
7 Wells Avenue
Newton, MA 02459
(617) 641-9000
Fax: (617) 641-9191
www.assistivetech.com
Circle # 24
See our ad on page 24

BigKeys Keyboard
P.O. Box 1888
Huntersville, NC 28078
(800) 249-5397
Fax: (704) 875-8936
http://www.bigkeys.com

EXCEPTIONAL PARENT IS IN BARNES & NOBLE.

YOU CAN FIND IT, BUY IT IN OVER 130 BARNES & NOBLE SUPERSTORES ALL ACROSS AMERICA, EVERY MONTH.

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ADAPTIVE HALLOWEEN COSTUMES
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SPECIAL REPORTS
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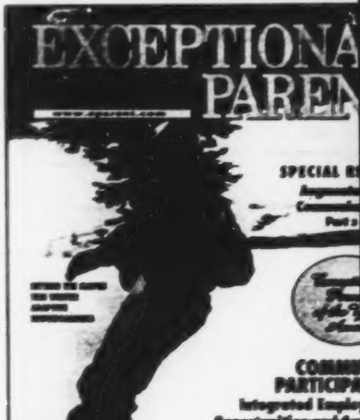
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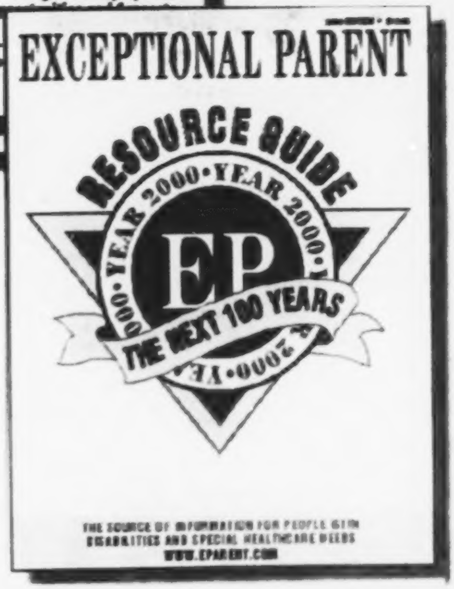
Integrated Employment

EXCEPTIONAL PARENT IS SOLD IN **BARNES & NOBLE SUPERSTORES, BORDERS, CROWN, ENCORE STORES, HASTINGS, LAURIATS & TOWER BOOKS.**

$4.50 COVER PRICE


EXCEPTIONAL PARENT
RESOURCE GUIDE
YEAR 2000
EP
THE NEXT 100 YEARS
THE SOURCE OF INFORMATION FOR PEOPLE WITH DISABILITIES AND SPECIAL HEALTHCARE NEEDS
WWW.EPARENT.COM

INCLUDING THE **JANUARY 2000 RESOURCE GUIDE:** GET AN EXTRA COPY FOR YOURSELF, OR FOR A FRIEND OR COLLEAGUE, AT BARNES & NOBLE.

$19.95 COVER PRICE

"The finest publication of its kind ... must reading for all those with a handicapped child ... a boon to parents ... it could change their lives."

ANN LANDERS, REPRINTED WITH PERMISSION OF ANN LANDERS, LOS ANGELES TIMES SYNDICATE/CREATOR SYNDICATE

Product & Services Directory

Prentke Romich Company
1022 Heyl Road
Wooster, OH 44691
Voice: (800) 262-1933
Fax: (330) 263-4829
✉ info@prentrom
www.prentrom.com
Circle # 106
See our ad on pages 72-73

Smart Input, Inc.
1460 Pittman Avenue
Sparks, NV 89431
(800) 366-8323
Fax: (775) 358-9675
www.smartinput.com
Portable word processing keyboard with features for the disabled.
Circle # 118
See our ad on page 95

DRIVING AIDS

Ricon Corporation
7900 Nelson Road
Panerama City, CA 91402
(818) 267-3000
Fax: (818) 267-3164
www.riconcorp.com
✉ sales@riconcorp.com
Circle #111
See our ad on page 81

EDUCATIONAL MATERIAL

AMDI
31 Watermill Lane
Great Neck, NY 11021
(516) 466-2288
Fax: (516) 466-2435
Circle #138
See our ad on page 79

American Printing House For The Blind, Inc.
1839 Frankfort Avenue,
P.O. Box 6085
Louisville, KY 40206-6085
(502) 899-2265
Fax: (502) 899-2363
www.aph.org 20
Circle # 21
See our ad on page 129

Different Roads to Learning
12 W. 18th Street 3 East
New York, NY 10011
(800) 853-1057

Goldberg & Osborne
915 W. Camelback
Phoenix, AZ 85013
1-800-THE-EAGLE (1-800-843-3245)
Fax: (602) 808-6950
www.1800theeagle.com
Circle # 60
See our ad on page 4

Kaplan Companies Inc.
1310 Lewisville-Clemmens Road
Lewisville, NC 27023
(800) 334-2014
www.kaplanco.com
Circle # 72
See our ad on page 175

Maddak, Inc.
6 Industrial Road
Pequannock, NJ 07440
(973) 628-7600
Fax: (973) 305-0841
✉ custservice@maddak.com 20
www.maddak.com
Circle # 81
See our ad on page 129

Poppin and Company
P.O. Box 176
Unity, ME 04988
(207) 437-2746
Fax: (207) 437-2404
Poppin specializes in AAC, articulation, and language materials that use DynaSyms®, the symbols on DynaVox® devices.

Pro-Ed, Inc.
8700 Shoal Creek Blvd.
Austin, TX 78757-6897
(512) 451-3246 (800) 897-3202
Fax: (512) 451-8542
(800) 397-7633
PRO-ED, Inc. is a leading publisher of assessments, therapy materials and resource/reference books in the areas of Speech, Language, and Hearing; Psychology; and Special Education. Free catalogs. (800) 897-3202.
Fax (800) 397-7633. Order online using our secure server at www.proedinc.com

Recording for the Blind & Dyslexic
20 Roszel Road
Princeton, NJ 08540
(800) 221-4792
Fax: (609) 987-8116
www.rfbd.org
RFB&D, an nonprofit volunteer organization, is the nation's largest lending library of educational books on tape for people who cannot read standard print effectively because of a disability.
Circle # 109
See our ad on page 68

Rock N' Learn, Inc.
P.O. Box 3595
Conroe, TX 77305
(800) 348-8445
Fax: (800) 801-5481
www.rocknlearn.com
Our "cool music that teaches" (audio and video) gets results with special needs students who benefit from high-interest multi-sensory instruction. Call for catalog or visit our web site.

Smart Input, Inc.
1460 Pittman Avenue
Sparks, NV 89431
(800) 366-8323
Fax: (775) 358-9675
www.smartinput.com
Portable word processing keyboard with features for the disabled.
Circle # 118
See our ad on page 95

ENVIRONMENTAL CONTROLS

AbleNet, Inc.
1081 Tenth Avenue S.E.
Minneapolis, MN 55414
(800) 322-0956
Fax: (612) 379-9143
www.ablenetinc.com 20

Prentke Romich Company
1022 Heyl Road
Wooster, OH 44691
Voice: (800) 262-1933
Fax: (330) 263-4829
✉ info@prentrom
www.prentrom.com
Circle # 106
See our ad on pages 72-73

FAST FOODS

Precision Foods, Inc.
2150 N. 15the Avenue
Melrose Park, IL 60160
Phone: (708) 216-07074
Fax: (708) 216-0709
✉ ppi2@iols.net
Circle # 105
See our ad on page 87

FINANCE/ESTATE/ PLANNING/INSURANCE

Metropolitan Life Insurance Company
One Madison Avenue
New York, NY 10010
(212) 578-8532
Fax: (212) 578-3164
www.metlife.com/specialneeds
MetDESK, Division of Estate Planning for Special Kids was established to extend MetLife's traditional commitment to public service to families of children with special needs. MetDESK is committed tohelping families through the maze of legal and financial complexities surrounding planning for the future of a child or dependent with special needs.
This includes preserving government benefits, meeting long term care needs, and structuring a plan to provide cash when it's needed most.
Circle # 91
See our ad on pages 66-67

Phoenix Home Life Mutual Insurance Company
One American Row
Hartford, CT 06115
(860) 403-5965
Fax: (860) 403-5708
www.phoenixspecialneeds.com
Circle # 102
See our ad on page 50

Special Needs Advocate for Parents (SNAP)
1801 Avenue of the Stars # 401
Los Angeles, CA 90067-5906
(888) 310-9889
Fax: (310) 201-9689
www.snapinfo.org
Circle #119
See our ad on page 170

FOOD & NUTRITION

International Nutrition, Inc.
11436 Cronridge Drive, Suite W
Owings Mills, MD 21117
(800) 899-3413 (410) 902-1760
Fax: (410) 902-1767
www.nutrivene.com
✉ ask@nutrivene.com
Circle # 70
See our ad on page 19

Pediatric Feeding Disorders Program at Children's Hospital
2924 Brook Road
Richmond, Virginia 23220
Information & Referrals (804) 228-5818
http://www.childrenshosp-richmond.org
Circle # 34
See our ad on page 112

Precision Foods, Inc.
2150 N. 15the Avenue
Melrose Park, IL 60160
Phone: (708) 216-07074
Fax: (708) 216-0709
✉ ppi2@iols.net
Circle # 105
See our ad on page 87

Ross Products Division
Abbott Laboratories
625 Cleveland Avenue
Columbus, OH 43215-1724
(614) 624-7677
www.rosslabs.com
Circle # 114
See our ad on pages 3, A, B

SHS North America
P.O. Box 117
Gaithersburg, MD 20884
(800) 365-7354
Fax: (301) 795-2301
www.shsna.com
SHS North America offers a wide variety of specialized nutritional products for the dietary management of clinical disorders.

The Ketogenic Cookbook
P.O. Box 8E
Gilman, CT 06336
(860) 873-3545
Fax: (860) 873-1311
The cookbook for the ketogenic diet

FURNITURE

Equipment Shop Inc.
P.O. Box 33
Bedford, MA 01730
1-800-525-7681
Fax: (781) 275 4094
We sell Tripp Trapp chairs from Norway in eight colors.
Accessories like tray, lap belt and pommel make the famous adjustable chair extremely versatile.
Circle # 54
See our ad on page 84

Hertz Supply Co. Inc.
4670 Schantz Road, Suite A
Allentown, PA 18104
(800) 321-4240
Fax: (610) 366-1808
www.hertzsupply.com
"The health care bed in disguise" that's the Volker style.
Circle # 65
See our ad on page 84

Kaplan Companies Inc.
1310 Lewisville-Clemmens Road
Lewisville, NC 27023
(800) 334-2014
www.kaplanco.com
Circle # 72
See our ad on page 175

Vail Products
235 First Street
Toledo, OH 43605
(800) 235-VAIL (8245)
Fax: (419) 698-1174
www.vailbed.com
Circle # 133
See our ad on Cover 4

HEADGEAR

Kaplan Companies Inc.
1310 Lewisville-Clemmens Road
Lewisville, NC 27023
(800) 334-2014
www.kaplanco.com
Circle # 172
See our ad on page 175

Plum Enterprises, Inc.
Exquisite Ergonomic ProtectiveWear™
500 Freedom View Lane
Post Office Box 85
Valley Forge, PA 19481
(610) 783-7377
Fax: (610) 783-7577
Toll Free: 1-800-321-PLUM
www.plument.com
Circle # 104
See our ad on page 80

HOBBIES & TOYS

Abilitations
1 Sportime Way
Atlanta, GA 30340
(800) 850-8602
Fax: (800) 845-1535
www.abilitations.com
Circle # 122
See our ad on page 28

Communication Aids for Children & Adults
6625 N. Sidney Place
Milwaukee, WI 53209
(414) 352-5678
Fax: (414) 352-5679
www.communicationaids.com

Downi Creations Inc.
1738 Nursery Hill Road
Columbia, SC 29212
(888) 749-9330
Fax: 803-749-2752
Circle # 71
See our ad on page 167

Playtex Products, Inc.
300 Nyala Farms Road
Westport, CT 06880
(800) 222-0453
www.PlaytexBaby.com
Circle # 103
See our ad on page 15

Southpaw Enterprises, Inc.
P.O. Box 1047
Dayton, OH 45401
1-800-228-1698
(937) 252-8502
www.southpawenterprises.com
Sensory integration and developmental products.
Circle # 121
See our ad on page 97

TFH (USA) Ltd.
4537 Gibsonia Road
Gibsonia, PA 15044
(800) 467-6222
Fax: (724) 444-6411
e-mail: info@tfhusa.com 20
Circle # 128
See our ad on page 78

HOME ADAPTATION/DESIGN

Barrier Free Lifts®, Inc.
9230 Prince William Street
Manassas, VA 20110
http://bfl-inc.com
Circle # 25
See our ad on page 68

INCONTINENCE PRODUCTS

ARC Home Health Products
101 Browne Street
Oneonta, NY 13820
(800) 278-8595
Fax: (607) 433-6745
e-mail: archhp@dmcom.net

Product & Services Directory

Columbia Medical Mfg. Corp.
P.O. Box 633
Pacific Palisades, CA 90272
(800) 454-6612
Fax: (310) 305-1718
www.columbiamedical.com
Circle # 37
See our ad on page 83

H.D.I.S.
9385 Dielman Industrial Drive
St. Louis, MO 63132
(800) 269-4663
Fax: (314) 997-0047
www.hdis.com
Circle # 62
See our ad on page 40

Kimberly-Clark Corporation
P.O. Box 2020
Neenah, WI 54857
Phone: (800) 544-1847
www.Kimberly-Clark.com
Circle # 74
See our ad on page 51

Principle Business Enterprises, Inc.
P.O. Box 129
Dunbridge, OH 43414-0129
(800) 467-3224
Fax: (419) 352-8340
www.gopeach.com
Circle # 107
See our ad on page 168

LISTENING AIDS

California Telephone Equipment Loan Program
505 14th Street, Suite 400
Oakland, CA 94612
(510) 302-1100
Fax: (510) 302-1130
www.ddtp.org
The California Telephone Equipment Loan Program provides FREE equipment to persons who have difficulty using the phone due to functional limitations affecting mobility, hearing, speech, cognition or vision.
Circle # 45
See our ad on page 172

MEDICAL EQUIPMENT DEALERS

Adaptivemall.com
Division of Bergeron Health Care
148 Spencer Road
Dolgeville, NY 13329
(315) 429-8407
Fax: (877) 694-4773
www.adaptivemall.com

American Discount Medical
3412 Clark Road
Sarasota, FL 34231
(800) 877-9100
Fax: (941) 923-7870
http://www.dhc.net/-adm
Never pay retail on medical equipment or supplies. Discounts given on the products that meet your requirements. Call for a quotation. We work with over 500 companies to satisfy your needs.

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Plymouth, WI 53073
(920) 459-8353
Fax: (800) 977-2256
e-mail:
ccpi@consumercareinc.com
www.consumercareinc.com
Circle # 38
See our ad on page 97

Direct Medical, Inc.
Incontinence and Wound Care
Promise and Harmonie Products
5422 Kiam Street
Houston, TX 77007
(713) 869-5585
Fax: (713) 869-5586
www.directmedicalinc.com
Toll Free: (800) 659-8037

Mobility Research
2209 W. 1st Street # 105
Tempe, AZ 85281
(480) 829-1727 (800) 332-9255
Fax: (480) 829-0737
e-mail: more@LiteGait.com
www.LiteGait.com
Makers of LiteGait® and WalkAble® partial weight bearing gait therapy devices that can be used for gait therapy, balance, coordination, pre-gait and standing activities. Can be used over a treadmill or over ground. Available for adults and children.
Circle # 92
See our ad on page 177

Northeast Mobility Center
94 Tayer Road
E. Nassau, NY 12062
(888) 224-3264

Woodbury Products
3580 Oceanside Road
Oceanside, NY 11558
1-800-777-1111
Fax: (516) 594-8315
Briefs, diapers, pads for less. Manufacturers coupons honored. Call for specials, samples! Closeouts 50% off retail.
Circle # 136
See our ad on page 38

PERSONAL CARE PRODUCTS

Invacare Corporation
One Invacare Way
Elyria, OH 44036
(800) 333-6900
Fax: 440-329-6568
www.invacare.com

Laclede Inc.
2030 East University Drive
Rancho Dominguez, CA 90220
(888) BIO-TENE
Fax: (310) 605-4288
Laclede Inc. is the proud manufacturer of such innovative oral care products for children as First Tooth Baby Toothpaste and Infadent teeth and gum massager. Laclede has also developed the only naturally antibacterial enzymatic oral care line called Biotene. Biotene toothpaste is created using a low foaming formula, detergent free (sodium lauryl sulfate). Biotene mouthwash is alcohol free and mild to use. Biotene chewing gum is sweetened with xylitol and Oralbalance is our moisturizing gel for dry mouth. All of Laclede oral hygiene products are sugar free.
Circle # 76
See our ad on page 41

Precision Foods, Inc.
2150 N. 15the Avenue
Melrose Park, IL 60160
Phone: (708) 216-07074
Fax: (708) 216-0709
✉ ppi2@iols.net
Circle # 105
See our ad on page 87

Principle Business Enterprises, Inc.
P.O. Box 129
Dunbridge, OH 43414-0129
(800) 467-3224
Fax: (419) 352-8340
www.gopeach.com
Circle # 107
See our ad on page 168

PHARMACEUTICAL PRODUCTS/SERVICES

Cyberonics, Inc.
16511 Space Center Blvd., Ste 600
Houston, TX 77058
(888) VNS-STIM
Fax: (281) 218-9332
www.cyberonics.com
Vagus Nerve Stimulation (VNS™)
Circle # 42
See our ad on page 111

Elan Pharmaceuticals
800 Gateway Blvd
South San Francisco, CA 94080
(650) 877-0900
Fax: (650) 877-8370
www.elanpharmaceuticals.com
Circle # 51
See our ad on pages 13-15

McNeil Consumer Products Co.
7050 Camp Hill Road
Ft. Washington, PA 19034
(800) 962-5357
Children's Motrin® is the most widely recommended pediatric ibuprofen fever reducer and pain reliever. Infant's and Children's Motrin® are available in three forms…suspension liquid, chewable tablets and swallowable caplets to meet the needs of your growing child.
Circle # 87
See our ad on page 35

Medtronic Neurological
800 53rd Avenue, NE
Minneapolis, MN 55421
(612) 514-5000
Fax: (612) 514-5078
www.itbtherapy.com
Medtronic Neurological's Intrathecal Baclofen (ITB?) therapy is an effective medical treatment for people with severe spasticity due to cerebral palsy, brain injury, multiple sclerosis, spinal cord injury and stroke.
Circle # 89
See our ad on page 5

Sigma-Tau Pharmaceuticals, Inc.
800 South Frederick Avenue, Suite 300
Gaithersburg, MD 20877
(800) 447-0169
www.sigma-tau.com
Circle # 117
See our ad on pages 2, A, B

Sore No More
150 E. Center Street
Moab, UT 84532
(435) 259-5931
Fax: (435) 259-5930
www.sorenomore.com
✉ moabking@lasal.net
Sore no more is a 100% all natural pain relieving gel that is used to relieve arthritic pain, muscle soreness, inflammation and back pain. Please call us at 1-800-842-6622 Ext. 127 and ask for a free sample. Nothing to lose except your pain.

PUBLISHERS

Charles C. Thomas, Publisher, Ltd.
2600 South First Street
Springfield, IL 62704
1-800-258-8980
Fax: (217) 789-9130
www.ccthomas.com 20
✉ books@ccthomas.com
Circle # 32
See our ad on page 127

Jason & Nordic
P.O. Box 441
Hollidaysburg, PA 16648
(814) 696-2920
Fax: (814) 696-4250
www.nb.net/?turtlbks/

Pro-Ed, Inc.
8700 Shoal Creek Blvd.
Austin, TX 78757-6897
(512) 451-3246
(800) 897-3202
Fax: (512) 451-8542
(800) 397-7633
PRO-ED, Inc. is a leading publisher of assessments, therapy materials and resource/reference books in the areas of Speech, Language, and Hearing; Psychology; and Special Education. Free catalogs. (800) 897-3202. 20 Fax: (800) 397-7633. Order online using our secure server at www.proedinc.com

Woodbine House
Publisher of the Special-Needs Collection
6510 Bells Mill Road
Bethesda, MD 20817
(800) 843-7323
Fax: (301) 897-5838
www.woodbinehouse.com
See our ad on page 204

RAMPS/LIFTS

Ascension
3526 E. Fort Lowell Road
Tucson, AZ 85716
(800) 459-0400
Fax: (520) 881-4983
www.wheelchairlift.com
NEW portable wheelchair lift for stages. ADA-compliant. Numerous safety features. One lift serves multiple locations. Fast setup. No installation costs. Automatic stage sensor. Quiet. Durable. 5 year warranty. Free Video.

Barrier Free Lifts®, Inc.
9230 Prince William Street
Manassas, VA 20110
http://bfl-inc.com
Circle # 25
See our ad on page 68

Ricon Corporation
7900 Nelson Road
Panorama City, CA 91402
(818) 267-3000
Fax: (818) 267-3164
www.riconcorp.com
✉ sales@riconcorp.com
Circle # 111
See our ad on page 81

The Braun Corporation
631 W. 11th Street
Winamac, IN 46996
1-800-THE LIFT
(219) 946-4670
Fax: (219) 946-4670
www.braunlift.com
Circle # 30
See our ad on page 96

REHABILITATION CENTERS/HOSPITALS

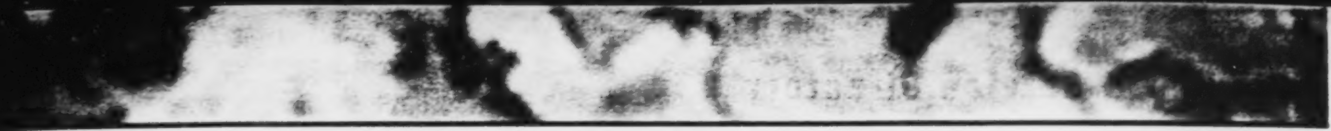
Baylor Pediatric Specialty Services
3301 Swiss Avenue
Dallas, TX 75204
1-888-7BAYLOR
www.baylorhealth.com/bpss
Children's hospital offering inpatient and outpatient services for children with physical and cognitive disabilities from traumatic injuries, and acute and chronic conditions.

BJC Human Performance Lab
4555 Forest Park, 2nd Floor
St. Louis, MO 63108
(314) 454-8288
Fax: (314) 454-5388
✉ jre6264@BJCmail.carenet.org
Circle # 29
See our ad on page 80

Children's Extended Care
22 Hillside Avenue
Groton, MA 01450
(978) 448-3388
Fax: (978) 448-9895
Providing long and short term healthcare, therapy and education in a residential setting for children and young adults with complex medical and developmental needs.
Circle # 33
See our ad on page 113

Children's Hospital
Comprehensive Pediatric Inpatient & Outpatient Rehabilitation Services; Medical-Surgical and Transitional Care; Physician Specialty Clinics; Multiple Locations.
2924 Brook Road
Richmond, Virginia 23220
Information & Referrals
(804) 228-5818
http://www.childrenshosp-richmond.org
Circle # 34
See our ad on page 112

Children's Specialized Hospital
150 New Providence Road
Mountainside, NJ 07092
(908) 233-3720
Fax: (908) 301-5576
Circle # 35
See our ad on page 179



Children's Specialized Hospital - Ocean
94 Stevens Road
Toms River, NJ 08755
(732) 914-1100
Fax: (732) 797-3830
Circle # 35
See our ad on page 179

Crotched Mountain Rehabilitation Center
1 Verney Drive
Greenfield, NH 03047
(603) 547-3311
Fax: (603) 547-3232
Fully accredited by the NEASC and CARF, the Crotched Mountain Rehabilitation Center offers the very best of residential and day programs for children with complex special needs. Visit our internet site at: http://www.cmf.org
Circle # 40
See our ad on page 125

Cumberland Hospital for Children
9407 Cumberland Road
New Kent, VA 23124
(800) 368-3472
Fax: (804) 966-2242
www.brownschools.com/cumberland

Kennedy Krieger Institute
707 N. Broadway
Baltimore, MD 21205
(888) 554-2080
Fax: (410) 502-8951
www.kennedykrieger.org
Kennedy Krieger Institute is an international leader dedicated to serving children and adolescents with patient care and innovative research.
Circle # 73
See our ad on page 166

Matheny School and Hospital
Box 339 Main Street
Peapack, NJ 07977
(908) 234-0011
Fax: (908) 234-2137
www.matheny.org
e-mail: info@matheny.org
Circle # 86
See our ad on page 165

Ocean Hyperbaric Center
4001 N. Ocean Boulevard
Lauderdale-By-The-Sea, FL 33308
(954) 771-4000
Fax: (954) 776-0670 20
Circle # 97
See our ad on page 38

The Med Group National ReHab Network
3223 S. Loop 289, Suite 600
Lubbock, TX 79423-9974
(800) 825-5633
Fax: (806) 793-6480
www.medrehab.net 20
Circle # 88
See our ad on page 77

SCHOOLS/CAMPS/RESIDENCES

Ability Camp, Inc.
Center for Conductive Education and Hyperbaric Oxygen Therapy
Providing separate and combined programs for children with C.P. For a free video call 1-800-442-6992.
www.abilitycamp.com
See our ad on page 207

Anne Carlsen Center for Children
301 7th Avenue NW
Jamestown, ND 58401
(800) 568-5175
Fax: (800) 568-5175
www.annecenter.org

Annandale Village
3500 Annandale Lane
Suwanee, GA 30024
(770) 945-8381
Fax: (770) 945-8693
www.annandale.org
Full residential and day programs paid vocational training, job placement, recreational activities, case mgt., creative and performing arts, meals & counseling.
Circle # 22
See our ad on page 160

Bancroft NeuroHealth
Hopkins Lane, P.O. Box 20
Haddonfield, NJ 08033-0018
(800) 774-5516
www.bnh.org
Programs in NJ, DE, LA & ME. Serving children and adults with Autism, developmental disabilities and brain injuries. Offering a full range of education, vocational, therapeutic, rehabilitation and residential programs, plus behavior intervention, day treatment and diagnostic outpatient services.

Benedictine Programs & Services
14299 Benedictine Lane
Ridgely, MD 21660
(410) 634-2112
Fax: (410) 634-2640
www.benschool.com
Circle # 26
See our ad on page 179

Berkshire Meadows
249 N. Plain Road
Housatonic, MA 02136
(413) 528-2523
Fax: (413) 528-0293
For people of all ages with severe developmental delay. They may be medically involved. We offer comprehensive and integrated medical residential and educational services. All therapeutic services are included.
www.berkshiremeadows.org
Circle #27
See our ad on page 78

Bethesda Lutheran Homes & Services, Inc.
700 Hoffman Drive
Watertown, WI 53094
(800) 369-4636
Fax: (920) 206-7706
www.blhs.org
Circle # 28
See our ad on page 180

BJC Human Performance Lab
4555 Forest Park, 2nd Floor
St. Louis, MO 63108
(314) 454-8288
Fax: (314) 454-5388
jre6264@BJCmail.carenet.org
Circle # 29
See our ad on page 80

Blind Children's Learning Center
18542-B Vanderlip
Santa Ana, CA 92705
(714) 573-8888
Fax: (714) 573-4944

Boston Higashi School
800 North Main Street
Randolph, MA 02368
(781) 961-0800
Fax: (781) 961-0888
www.bostonhigashi.org
The International Program Serving Individuals with Autism. Affiliate Musashino Higashi Gakuen, Japan

Camp Loyaltown AHRC
115 East Bethpage Road
Plainview, NY 11803-4299
(516) 293-1111 Ext. 608
Fax: (516) 719-8100
www.ahrc.org
Loyaltown is a summer recreational respite camp in the Catskill Mtns. at Hunter New York serving children & adults with mild and moderate developmental disabilities.

Camphill Special School
1784 Fairview Road
Glenmoore, PA 19343
(610) 469-9236
Fax: (610) 469-9758
www.beaverrun.org
See our ad on page 207

Children's Care Hospital & School
2501 W. 26th Street
Sioux Falls, SD 57105-2498
(605) 782-2300 or (800) 584-9294
Private, nonprofit facility with outreach, outpatient, day & summer school and residential services for children with disabilities.
Pediatric & adult outpatient services now offered at the CCHS Rehabilitation Center, 1100 W. 41st Street. Accredited rehabilitation programs.
http://www.cchs.org
See our ad on page 207

Children's Extended Care
22 Hillside Avenue
Groton, MA 01450
(978) 448-3388
Fax: (978) 448-9695
Providing long and short term healthcare, therapy and education in a residential setting for children and young adults with complex medical and developmental needs.
Circle # 33
See our ad on page 113

Chileda Institute
1020 Mississippi Street
LaCrosse, WI 54601
(608) 782-6480
Fax: (608) 782-6481
www.chileda.org
Circle # 36
See our ad on page 181

CIB/Oak Hill School
120 Holcomb Street
Hartford, CT 06112
(860) 242-2274
Fax: (860) 242-3103
Our community-based education and residential programs provide students with multiple disabilities every opportunity to reach their highest potential.
www.ciboakhill.org
Circle # 96
See our ad on page 164

Cotting School
453 Concord Avenue
Lexington, MA 02421
(781) 862-7323
Fax: (781) 861-1179
www.cotting.org

Devereux
444 Devereux Drive
P.O. Box 638
Villanova, PA 19085
Toll Free (800) 935-6789
(610) 542-3030
Fax: (610)542-3141
Devereux-A nationwide network of residential and day treatment programs for children and adults who have a wide range of emotional and or developmental disabilities.
Circle # 46
See our ad on page 26

Elwyn
111 Elwyn Road
Elwyn, PA 19063
Phone: (610) 891-2256
Fax: (610) 891-7600
Over 140 years of teaching children with special needs. Day and residential for birth to 21 years. Early intervention, integrated preschool, elem., secondary and alternative Ed., Residential, clinical, physical and recreational therapies. Trust our experience.
www.elwyn.org

Evergreen Center
345 Fortune Blvd.
Milford, MA 01757
(508) 478-2631
Fax: (508) 634-3251
www.evergreenctr.org
Circle # 55
See our ad on page 93

Fencliff Manor
1154 Saw Mill River Road
Yonkers, NY 10710
(914) 968-4854
Fax: 914-968-4857
✉ femcliff@aol.com

Heartspring
8700 East 29th Street N.
Wichita, KS 67226
(800) 835-1043
Fax: (316) 634-0555
Our new campus provides a positive, practical environment for multidisciplinary programs that include education, life skills, communication, and behavior management. We serve children ages 5-21 with multiple disabilities.
www.heartspring.org
Circle # 23
See our ad on page 173

HMS School for Children with Cerebral Palsy
4400 Baltimore Avenue
Philadelphia, PA 19104
(215) 222-2566
Fax: (215) 222-1889
Circle # 66
See our ad on page 180

IDDI, Crystal Springs School
38 Narrows Road
Assonet, MA 02702
(800) 84J-8087 Ext. 434
Fax: (508) 644-3101 Ext. 372
✉ Css372@aol.com 20
Circle # 41
See our ad on page 148

Lakeview NeuroRehabilitation Center
101 Highwater Road
Effingham Falls, NH 03814
(800) 473-4221
Fax: (603) 539-8888
www.lakeviewsystem.com
Circle # 77
See our ad on page 129

Martha Lloyd Community Services
190 W. Main Street
Troy, PA 16947
(570) 297-2185
www.marthalloyd.org
Circle # 85
See our ad on page 182

Melmark
2600 Wayland Road
Berwyn, PA 19312
(888) MELMARK
Fax: (610) 353-4956
www.melmark.org
Approved private school, adult day programs, on/off campus residential alternatives for people with disabilities; 24 hour nursing care, OT/PT, speech, aquatics, horsemanship, recreation, multi-sensory programs. Call for more information.
Circle # 90
See our ad on page 29

New England Villages
664 School Street
Pembroke, MA 02359
(781) 293-5461
Fax: (781) 294-8385
✉ info@newenglandvillage.org
See our ad on page 78

Pathfinder Village for Down Syndrome
RR #1 32-A
Edmeston, NY 13335
(607) 965-8377
See our ad on page 206

Resources for Children with Special Needs, Inc.
200 Park Avenue South, Suite 816
New York, NY 10003
(212) 677-4650
Complete up-to-date Guide to New York City day camps and summer programs in the northeast for children with special needs. Order direct from Resources, Dept. EPM. $20 + $4.50 postage/handling. Prepay by check or credit card. Fax: (212) 254-4070. Visit us on the WEB at
www.resourcesnyc.org

Riverbrook Residence, Inc.
4 Ice Glen Road, P.O. Box 478
Stockbridge, MA 01262
(413) 298-4926
www.riverbrook.org
Circle #112
See our ad on page 40

St. Coletta of Wisconsin, Inc.
W4955 Hwy 18
Jefferson, WI 53549
(920) 674-4330
Fax: (920) 674-4603
www.msmicro.com/stcoleta
Circle # 123
See our ad on page 128

St. Vincent's Special Needs Services
95 Merritt Blvd.
Trumbull, CT 06611
(203) 375-6400
Fax: (203) 380-1190
✉ feroleto.child.dev@snet.net
Providing education and therapeutic day programs for children, 0-21 with multiple medical/developmental needs.
Circle # 124
See our ad on page 171

Stewart Home School
4200 Lawrenceburg Road Dept. B
Frankfort, KY 40601
(502) 227-4821
Fax: (502) 227-3013
www.stewarthome.com 20
Circle # 125
See our ad on page 126

The Center for Discovery
P.O. Box 840
Harris, NY 12742-0840
(914) 794-1400 Ext. 1444
Fax: (914) 794-1615
e-mail: admiss@sdtc.org
Provides innovative and comprehensive services to children who have multiple disabilities and medical frailties. State-of-the-art, accessible, 50 acre campus. Come see us in action. We're like nothing you've ever seen.
Circle # 126
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The Duvall Home
Presbyterian Special Services, Inc.
3395 Grand Avenue
P.O. Box 220036
Glenwood, FL 32722
(904) 734-2874 (888) 445-4722
✉duvall@intersrv.com
Circle # 48
See our ad on page 84

The Ledges
P.O. Box 38
Hopedale, MA 01747-0038
(508) 473-6520
Fax: (508) 478-3054
A residential and educational center for developmentally disabled adults, aged 18 and older. Offers both campus style and community-based housing.

The Lukas Community
P.O. Box 137
Temple, NH 03084
(603) 878-4796
www.mv.com/org/lukas 20
See our ad on page 206

The New England Center for Children
33 Turnpike Road
Southboro, MA 01772
(508) 481-1015
Fax: (508) 485-3421
State of the art day/residential school and group homes for children with autism, PDD, developmental disabilities & behavior disorders, age 3-22. Curriculum covers communication, academics, social & life-skills, employment.
http://www.necc.org
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SEATING & POSITIONING

Abilitations
1 Sportime Way
Atlanta, GA 30340
(800) 850-8602
Fax: (800) 845-1535
www.abilitations.com
Circle # 122
See our ad on page 28

Altimate Medical, Inc.
P.O. Box 180
262 W. 1st Street
Morton, MN 56270
(800) 342-8968 (507) 697-6393
Fax: (507) 697-6900
✉ info@easystand.com
www.easystand.com 20
Circle # 84
See our ad on page 126

Columbia Medical Mfg. Corp.
P.O. Box 633
Pacific Palisades, CA 90272
(800) 454-6612
Fax: (310) 305-1718
www.columbiamedical.com
Circle # 37
See our ad on page 83

Convaid
2830 California Street
Torrance, CA 90503
(310) 539-6814
Fax: (310) 539-3670
www.convaid.com
Circle # 39
See our ad on page 25

Equipment Shop Inc.
P.O. Box 33
Bedford, MA 01730
1-800-525-7681
Fax: (781) 275 4094
We sell Tripp Trapp chairs from Norway in eight colors. Accessories like tray, lap belt and pommel make the famous adjustable chair extremely versatile.
Circle # 54
See our ad on page 84

Kaplan Companies Inc.
1310 Lewisville-Clemmens Road
Lewisville, NC 27023
(800) 334-2014
www.kaplanco.com
Circle # 72
See our ad on page 175

Matheny School and Hospital
Box 339 Main Street
Peapack, NJ 07977
(908) 234-0011
Fax: (908) 234-2137
www.matheny.org
✉ info@matheny.org
Circle # 86
See our ad on page 165

Mulholland Positioning Systems, Inc.
P.O. Box 391
Santa Paula, CA 93061
(800) 543-4769
Fax: (805) 933-1082

Otto Bock Rehab
3000 Xenium Lane
Minneapolis, MN 55441
(800) 328-4058
www.ottobockus.com
Circle # 98
See our ad on page 47

Permobil
68 Gill Street
Woburn, MA 01801
(781) 932-9009
Fax: (781) 932-0428
✉ permobil@aol.com
Circle # 101
See our ad on page 71

R.E.A.L. Design
187 S. Main Street
Dolgeville, NY 13329
(800) 696-7041
Fax: (315) 429-3071
www.disabilitymall.com/real/
Circle # 108
See our ad on page 174

Sammons Preston
4 Sammons Court
Bolingbrook, IL 60440-4989
(800) 323-5547
Fax: (800) 547-4333
✉ sp@sammonspreston.com
www.sammonspreston.com
Circle # 115
See our ad on page 38

Snug Seat, Inc.
12801 E. Independence Blvd.
Stallings, NC 28105
(800) 336-7684
Fax: (704) 882-0751
www.snugseat.com
Circle # 120
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Theradyne, Division of Kurt Mfg
395 Ervin Industrial Drive
Jordan, MN 55352-1062
(800) 328-4014
www.theradyne.com
Circle # 131
See our ad on page 12

SOFTWARE

Assistive Technology, Inc.
7 Wells Avenue
Newton, MA 02459
(617) 641-9000
Fax: (617) 641-9191
www.assistivetech.com
Circle # 24
See our ad on page 24

CapMed Corporation
Personal Health Record
7202 Waterford Trace
Huntsville, AL 35802
(256) 881-6030
www.capmed.com
Circle # 31
See our ad on page 82

DynaVox Systems, Inc.
2100 Wharton Street, Suite 400
Pittsburgh, PA 15203
(888) 697-7332
Fax: (412) 381-5241
www.dynavoxsys.com
Circle # 49
See our ad on page 99

Laureate Learning Systems, Inc.
110 E. Spring Street
Winooski, VT 05404
(800) 562-6801
Fax: (802) 655-4757
www.LaureateLearning.com

SPORTS/RECREATION/FAMILY

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American Airlines® and 20 American Eagle® together serve over 250 cities in over 40 countries worldwide. For more information or reservations call your Travel Agent or American at 1-800-433-7300 or book online at aa.com™.
Circle # 19
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Flaghouse, Inc.
601 Flaghouse Drive
Hasbrouck Heights, NJ 07604-3116
(800) 793-7900
Fax: (800) 793-7922
www.flaghouse.com
✉ info@flaghouse.com
Flaghouse offers a full range of developmental and physical disability equipment and therapy aids, including products for positioning, gross- and fine-motor work, sensory stimulation, walkers, standers, ride-ons, and manipulatives. Also featured prominently are the Flying Colors™ line of ability switches and communication devices, the Intellisense™ interactive mumtimedia therapy system, Enfold™ seating for continuing care, and the complete SNOEZELEN® multi-sensory approach and product line. Call (800) 793-7900 or Fax (800) 793-7922 for a catalog.
Circle # 57
See our ad on page 2

Innovative Products
830 South 48th Street
Grand Forks, ND 58201
(701) 772-5185 (800) 950-5185
Fax: (701) 772-5284
✉ jsteinke@iphope.com
The GO-KART is fun to drive and experience freedom and independence without worrying about being too heavy or tipping.
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Playworld Systems, Inc.
1000 Buffalo Road
Lewisburg, PA 17837
(800) 233-8404
Fax: (570) 522-3030
www.playworldsystems.com
Global leaders in design, manufacture and installation of Accessible Playgrounds.

Plum Enterprises, Inc.
Exquisite Ergonomic ProtectiveWear™
500 Freedom View Lane
Post Office Box 85
Valley Forge, PA 19481
(610) 783-7377
Fax: (610) 783-7577
Toll Free: 1-800-321-PLUM
www.plument.com
Circle # 104
See our ad on page 80

Rock N' Roll Therapy Cycles
P.O. Box 1558
Levelland, TX 79336
(800) 654-9664
Fax: (806) 894-1238
www.rocknrollcycles.com
Outdoor therapy cycles designed for fun! Cycles for all ages & needs, from 2 yrs. thru adults. Especially for Spina Bifida, CP, Blindness, etc.

Seat-A-Robics
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James Town, NC 27282
(336) 454-4615
Fax: (336) 454-4615
http://www.seat-a-robics.com

STANDING EQUIPMENT

Altimate Medical, Inc.
P.O. Box 180
262 W. 1st Street
Morton, MN 56270
(800) 342-8968 (507) 697-6393
Fax: (507) 697-6900
✉ info@easystand.com
www.easystand.com 20
Circle # 84
See our ad on page 126

DavisMade, Inc.
5316 Lapeer Road
Burton, MI 48509
(810) 742-0581
Fax: (810) 715-0946
www.standingani.com
Pediatric Mobile Prone Stander
Circle # 44
See our ad on page 98

Innovative Products
830 South 48th Street
Grand Forks, ND 58201
(701) 772-5185 (800) 950-5185
Fax: (701) 772-5284
✉ jsteinke@iphope.com
Our Standing Frames can be purchased in either a supine or prone version. All Standing Frames will work in our GO-BOT.
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Kaplan Companies Inc.
1310 Lewisville-Clemmens Road
Lewisville, NC 27023
(800) 334-2014
www.kaplanco.com
Circle # 72
See our ad on page 175

Snug Seat, Inc.
12801 E. Independence Blvd.
Stallings, NC 28105
(800) 336-7684
Fax: (704) 882-0751
www.snugseat.com
Circle # 120
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Theradyne, Division of Kurt Mfg
395 Ervin Industrial Drive
Jordan, MN 55352-1062
(800) 328-4014
www.theradyne.com
Circle # 131
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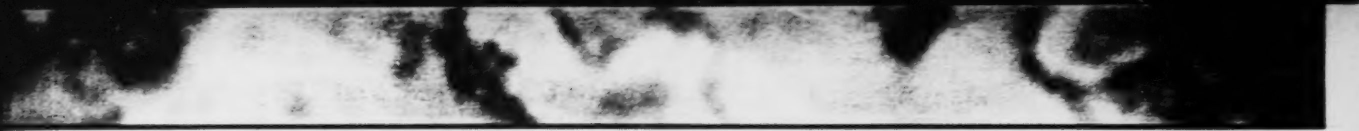
STROLLERS

Columbia Medical Mfg. Corp.
P.O. Box 633
Pacific Palisades, CA 90272
(800) 454-6612
Fax: (310) 305-1718
www.columbiamedical.com
Circle # 37
See our ad on page 83



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2830 California Street
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(310) 539-6814
Fax: (310) 539-3670
www.convaid.com
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3000 Xenium Lane
Minneapolis, MN 55441
(800) 328-4058
www.ottobockus.com
Circle # 98
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The Baby Jogger Company
P.O. Box 2189
Yakima, WA 98907
(800) 241-1848
Fax: (509) 453-7732
www.babyjogger.com
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1-800-THE LIFT
(219) 946-4670
Fax: (219) 946-4670
www.braunlift.com
Circle # 30
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Freedom Wheelchair Lifts, Inc.
1084 Katy Road
Keller, TX 76248
(817) 431-9437
Fax: (817) 431-2292
www.vansrus.com

Motion Automotive Specialty
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Brimfield, MA 01010
(413) 245-9949
(800) 955-9949
www.motionautomotive.com 20

Ricon Corporation
7900 Nelson Road
Panerama City, CA 91402
(818) 267-3000
Fax: (818) 267-3164
www.riconcorp.com
✉ sales@riconcorp.com
Circle # 111
See our ad on page 81

VAN RENTALS

Wheelchair Getaways, Inc.
P.O. Box 605
Versailles, KY 40383
(800) 642-2042
Fax: (606) 873-8039
www.wheelchair-getaways.com
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(818) 267-3000
Fax: (818) 267-3164
www.riconcorp.com
✉ sales@riconcorp.com
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See our ad on page 81

The Braun Corporation
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Winamac, IN 46996
1-800-THE LIFT
(219) 946-4670
Fax: (219) 946-4670
www.braunlift.com
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Volkswagen
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Fax: (248) 340-5694
✉ mike.allen@ps.net
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20102 Woodbine Avenue
Castro Valley, CA 94546
(800)549-6999
Fax: (510) 582-5911
www.exceptionalteaching.com
✉ exteaching@aol.com
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Light Bright Books
2930 E. 4th Avenue
Durango, CO 81301
(970) 259-0563
Fax: (970) 259-0563
www.lightbrightbooks.com
See our ad on page 205

National Family Association for Deaf-Blind
111 Middle Neck Road
Sands Point, NY 11050
Phone: (800) 255-0411
Fax: (516) 883-9060
Circle # 93
See our ad on page 104

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4-3995 Sladeview Crescent
Mississauga, ON L5L 5Y1 Canada
(905) 607-4022
Fax: (905) 607-9099
✉ walk@aodmobility.com
www.aodmobility.com
Circle # 83
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Hart Independent Mobility Corp.
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Fax: (905) 403-9973
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www.invacare.com

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Minneapolis, MN 55441
(800) 328-4058
www.ottobockus.com
Circle # 98
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Red Barn Enterprises, Inc.
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Phoenix, AZ 85015
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Fax: (602) 242-9211
Circle # 110
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Jupiter, FL 33458
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Fax: (781) 932-0428
✉ permobil@aol.com
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Deming Design, Inc.
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✉: kmdeming@aol.com
www.beachwheelchair.com

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2241 Madera Road
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(805) 582-0077
(800) 331-8551
Fax: (805) 582-1509
Circle # 58
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Elyria, OH 44036
(800) 333-6900
Fax: 440-329-6568
www.invacare.com

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12801 E. Independence Blvd.
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Fax: (704) 882-0751
www.snugseat.com
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395 Ervin Industrial Drive
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(800) 328-4014
www.theradyne.com
Circle # 131
See our ad on page 12

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(800) 331-8551
Fax: (805) 582-1509
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Fort Wayne, Indiana 46825
(800) 554-8044
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Pediatric Powered Mobility
Circle #
Circle # 59
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Elyria, OH 44036
(800) 333-6900
Fax: 440-329-6568
www.invacare.com

Permobil
68 Gill Street
Woburn, MA 01801
(781) 932-9009
Fax: (781) 932-0428
✉ permobil@aol.com
Circle # 101
See our ad on page 71

Sunrise Medical 20
7477 E. Dry Creek Parkway
Longmont, CO 80503
(888) 333-2572
(303) 218-4575
Circle # 127
See our ad on page 9

Theradyne, Division of Kurt Mfg
395 Ervin Industrial Drive
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(800) 328-4014
www.theradyne.com
Circle # 131
See our ad on page 12

OTHER

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Fax: (516) 466-2435
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Fax: (310) 539-3670
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See our ad on page 25

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Circle # 71
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(800) 222-0453
www.PlaytexBaby.com
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www.snapinfo.org
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www.careelectronics.com

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✉ friends@pathwaysawareness.org
Circle # 100
See our ad on page 128

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1-800-THE-EAGLE
(1-800-843-3245)
Fax: (602) 808-6950
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See our ad on pages 48-49

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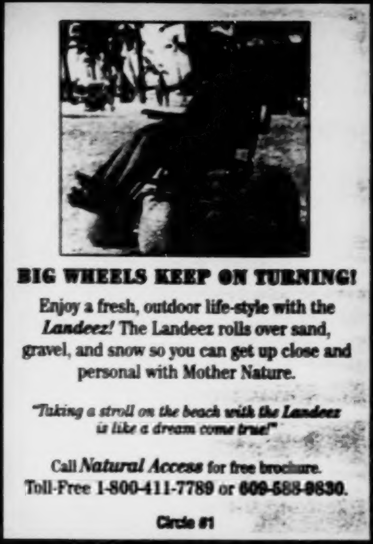

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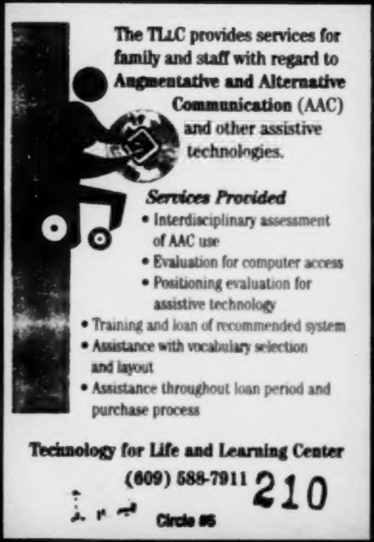

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2000 Editorial Calendar

Technology, mobility, healthcare, sports and recreation, learning disabilities, early intervention, organizations, and **finance** are the **core topics** covered extensively and often in EXCEPTIONAL PARENT Magazine. Each issue will also include a special section, a cluster of in-depth features on a single topic.

Here are the themes you can look forward to seeing in 2000:

FEBRUARY	**Early Childhood**
MARCH	**Medical Research Update**
APRIL	**11th Annual Mobility Issue**
MAY	**Recreation, Sports and Play**
JUNE	**Technology in Education & Daily Living**
JULY	**Adolescence and Transitioning**
AUGUST	**Healthcare**
SEPTEMBER	**Annual Education Issue**
OCTOBER	**Toy and Holiday Activities**
NOVEMBER	**Technology**
DECEMBER	**Family, Friends & The Community**

Regular columns include Ask the Doctor, Search and Respond, Organizational Spotlight, Role Models, EXCEPTIONAL PARENT Web site, and the Children's Page.

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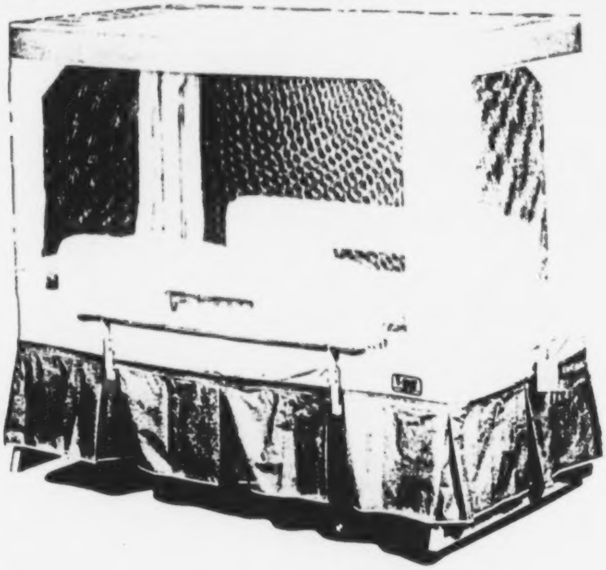

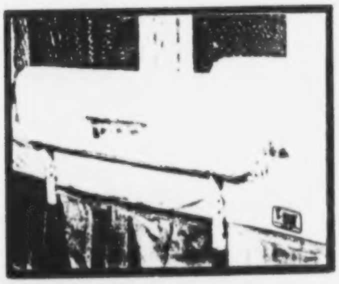

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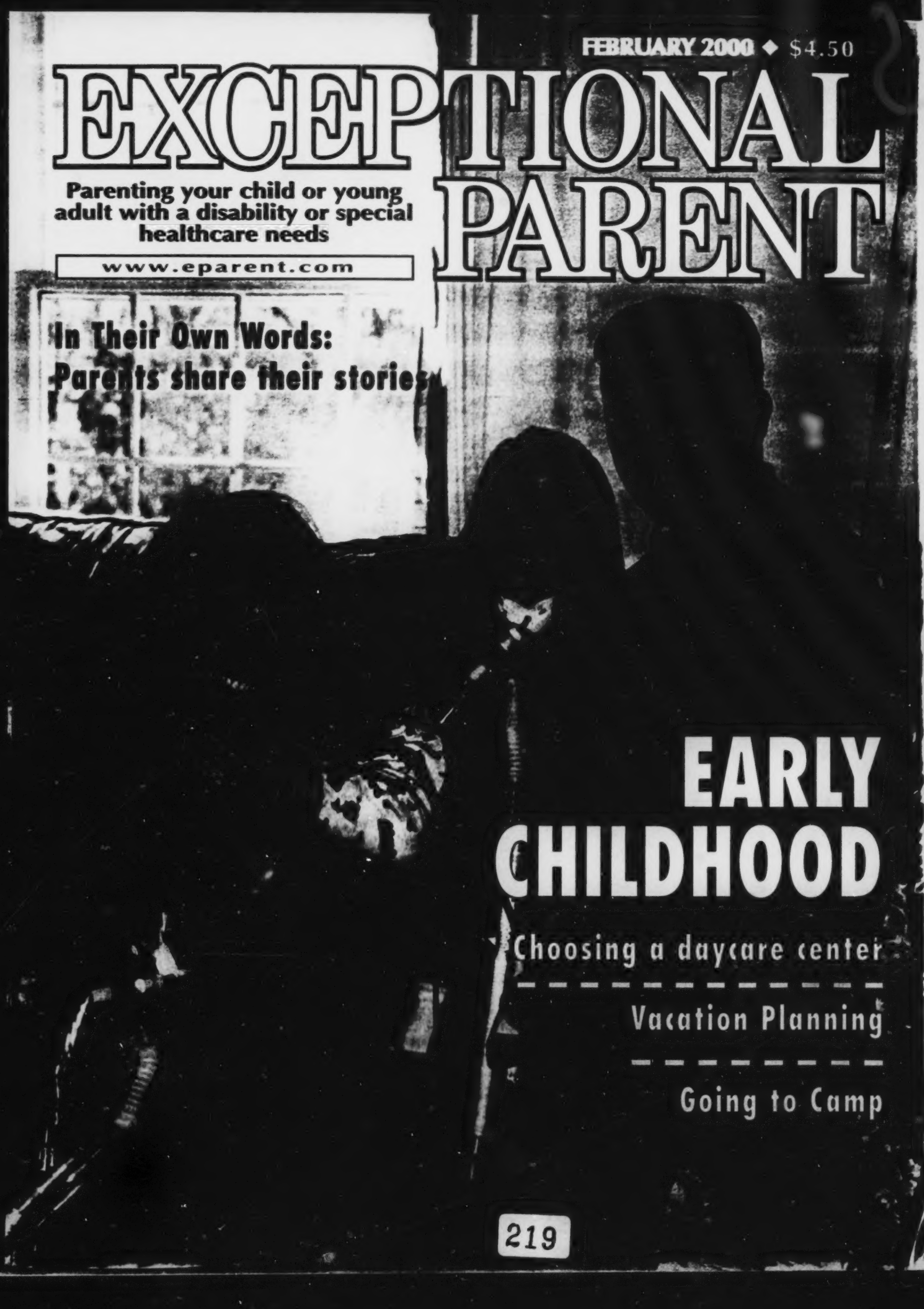

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- premature birth
- administration of carnitine- free TPN
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CARNITOR® (Levocarnitine) Injection 1 g per 5 mL and 500 mg per 2.5 mL. FOR INTRAVENOUS USE ONLY. Brief Summary of Prescribing Information. (Please see package insert for full prescribing information.) **Description:** Levocarnitine is a carrier molecule in the transport of long chain fatty acids across the inner mitochondrial membrane. CARNITOR® (Levocarnitine) Injection is a sterile aqueous solution containing 1 g of levocarnitine per 5 mL ampoule and 500 mg of levocarnitine per 2.5 mL ampoule. The pH is adjusted to 6.0 - 6.5 with hydrochloric acid. Chemically, levocarnitine is (R)-3-carboxy-2-hydroxy-N,N,N-trimethyl-I-propanaminium hydroxide, inner salt. It is a white powder with a melting point of 196-197–C and is readily soluble in water, hot alcohol, and insoluble in acetone. The pH of a solution (1 in 20) is between 6-8 and its pKa value is 3.8. Its chemical structure is: **Empirical formula:** $C_7H_{15}NO_3$ **Molecular weight:** 161.20. **Clinical pharmacology:** CARNITOR® (Levocarnitine) is a naturally occurring substance required in mammalian energy metabolism. It has been shown to facilitate long-chain fatty acid entry into cellular mitochondria, therefore delivering substrate for oxidation and subsequent energy production. Fatty acids are utilized as an energy substrate in all tissues except the brain. In skeletal and cardiac muscle they serve as major fuel. Primary systemic carnitine deficiency is characterized by low plasma, RBC, and/or tissue levels. It has not been possible to determine which symptoms are due to carnitine deficiency and which are due to the underlying organic acidemia, as symptoms of both abnormalities may be expected to improve with carnitine. The literature reports that carnitine can promote the excretion of excess organic or fatty acids in patients with defects in fatty acid metabolism and/or specific organic acidopathies that bioaccumulate acyl CoA esters. Secondary levocarnitine deficiency can be a consequence of inborn errors of metabolism. CARNITOR® (Levocarnitine) may alleviate the metabolic abnormalities of patients with inborn errors that result in accumulation of toxic organic acids. Conditions for which this effect was demonstrated are: glutaric aciduria II, methyl malonic aciduria, propionic acidemia, and medium chain fatty acyl CoA dehydrogenase deficiency. Autointoxication occurs in these patients due to the accumulations of acyl CoA compounds that disrupt intermediary metabolism. The subsequent hydrolysis of the acyl CoA compound to its free acid results in acidosis that can be life threatening. Levocarnitine clears the acyl CoA compound by formation of acyl carnitine which is quickly excreted. Levocarnitine deficiency is defined biochemically as abnormally low plasma levels of free carnitine, less than 20 µmol/L at one week post term and may be associated with low tissue and/or urine levels. Further, this condition may be associated with a ratio of plasma ester/free levocarnitine levels greater than 0.4 or abnormally elevated levels of esterified levocarnitine in the urine. In premature infants and newborns, secondary deficiency is defined as plasma free levocarnitine levels below age related normal levels. **Indications and usage:** For the acute and chronic treatment of patients with an inborn error of metabolism that results in secondary carnitine deficiency. **Contraindications:** None known. **Warnings:** None. **Precautions:** Carcinogenesis, mutagenesis, impairment of fertility - Mutagenicity tests performed in *Salmonella typhimurium*, *Saccharomyces cerevisiae*, and *Schizosaccharomyces pombe* indicate that levocarnitine is not mutagenic. No long-term animal studies have been performed to evaluate the carcinogenic potential of levocarnitine. It should be consumed slowly and doses should be spaced evenly throughout the day to maximize tolerance. **Pregnancy:** Pregnancy Category B - Reproductive studies have been performed in rats and rabbits at doses up to 3.8 times the human dose on the basis of surface area and have revealed no evidence of impaired fertility or harm to the fetus due to CARNITOR® (Levocarnitine). There are, however, no adequate and well controlled studies in pregnant women. Because animal reproduction studies are not always predictive of human response, this drug should be used during pregnancy only if clearly needed. **Nursing mothers:** It is not known whether this drug is excreted in human milk. Because many drugs are excreted in human milk, a decision should be made whether to discontinue nursing or to discontinue the drug, taking into account the importance of the drug to the mother. **Pediatric use:** See Dosage and administration. **Adverse reactions:** Transient nausea and vomiting have been observed. Less frequent adverse reactions are body odor, nausea, and gastritis. An incidence for these reactions is difficult to estimate due to the confounding effects of the underlying pathology. Seizures have been reported to occur in patients with or without pre-existing seizure activity receiving either oral or intravenous levocarnitine. In patients with pre-existing seizure activity, an increase in seizure frequency and/or severity has been reported. **Overdosage:** There have been no reports of toxicity from levocarnitine overdosage. The oral LD50 of levocarnitine in mice is 19.2 g/kg. Large doses of levocarnitine may cause diarrhea. **Dosage and administration:** CARNITOR® (Levocarnitine) Injection is administered intravenously. The recommended dose is 50 mg/kg given as a slow 2-3 minute bolus injection or by infusion. Often a loading dose is given in patients with severe metabolic crisis followed by an equivalent dose over the following 24 hours. It should be administered q3h or q4h, and never less than q6h either by infusion or by intravenous injection. All subsequent daily doses are recommended to be in the range of 50 mg/kg or as therapy may require. The highest dose administered has been 300 mg/kg. It is recommended that a plasma carnitine level be obtained prior to beginning this parenteral therapy. Weekly and monthly monitoring is recommended as well. This monitoring should include blood chemistries, vital signs, plasma carnitine concentrations (the plasma free carnitine level should be between 35 and 60 micromoles/liter) and overall clinical condition. Parenteral drug products should be inspected visually for particulate matter and discoloration prior to administration, whenever solution and container permit. **Compatibility and stability:** CARNITOR® (Levocarnitine) Injection is compatible and stable when mixed in parenteral solutions of Sodium Chloride 0.9% or Lactated Ringer's in concentrations ranging from 250 mg/500 mL (0.5 mg/mL) to 4200 mg/500 mL (8.0 mg/mL) and stored at room temperature (25° C) for up to 24 hours in PVC plastic bags. **How supplied:** CARNITOR® (Levocarnitine) Injection, 200 mg per 1 mL, is available in 5 mL single dose ampoules packaged 5 ampoules per carton (NDC 54482-146-09) and in 2.5 mL single dose ampoules packaged 5 ampoules per carton (NDC 54482-146-10). Made in Italy. Store ampoules at controlled room temperature (25° C). See USP. Store in carton until their use to protect from light. Discard unused portion of an opened ampoule, as they contain no preservative. CARNITOR® (Levocarnitine) is also available in the following dosage forms for oral administration: CARNITOR® (Levocarnitine) Tablets are supplied as 330 mg tablets embossed with "CARNITOR ST" in individual blisters, packaged in boxes of 90 (NDC 54482-144-07). Made in Italy. CARNITOR® (Levocarnitine) Oral Solution, is supplied in 118 mL (4 FL. OZ.) multiple-unit plastic containers. The multiple-unit containers are packaged 24 per case (NDC 54482-145-08). CARNITOR® (Levocarnitine) Oral Solution is manufactured for Sigma-Tau Pharmaceuticals, Inc. By: Alpharma USPD, Inc. Baltimore, MD 21244-2654 and/or for Hi-Tech Pharmacal Co., Inc. Amityville, NY 11701. **Rx only.**

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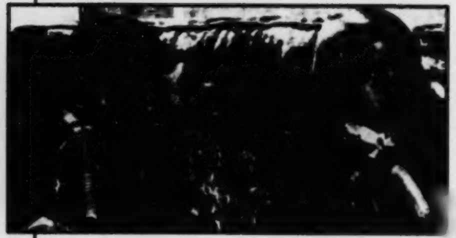

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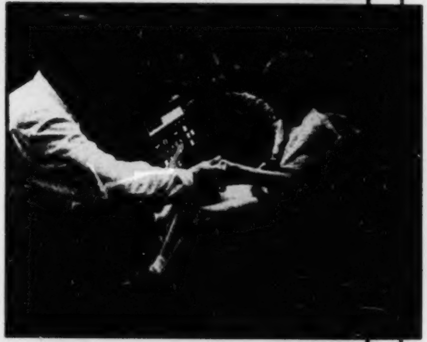

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COVER: EP Hall of Fame Exceptional Family, the Crowleys, at home in Pennington, NJ. (Clockwise from bottom left: Patrick, Aileen, John, Jr., Megan, and John, Sr.) How they face the challenge presented by Pompe's disease starts on page 22. PHOTO BY MICHAEL LONGOBARDI.

EXCEPTIONAL PARENT
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EXCEPTIONAL PARENT
Parenting your child or young adult with a disability or special healthcare needs

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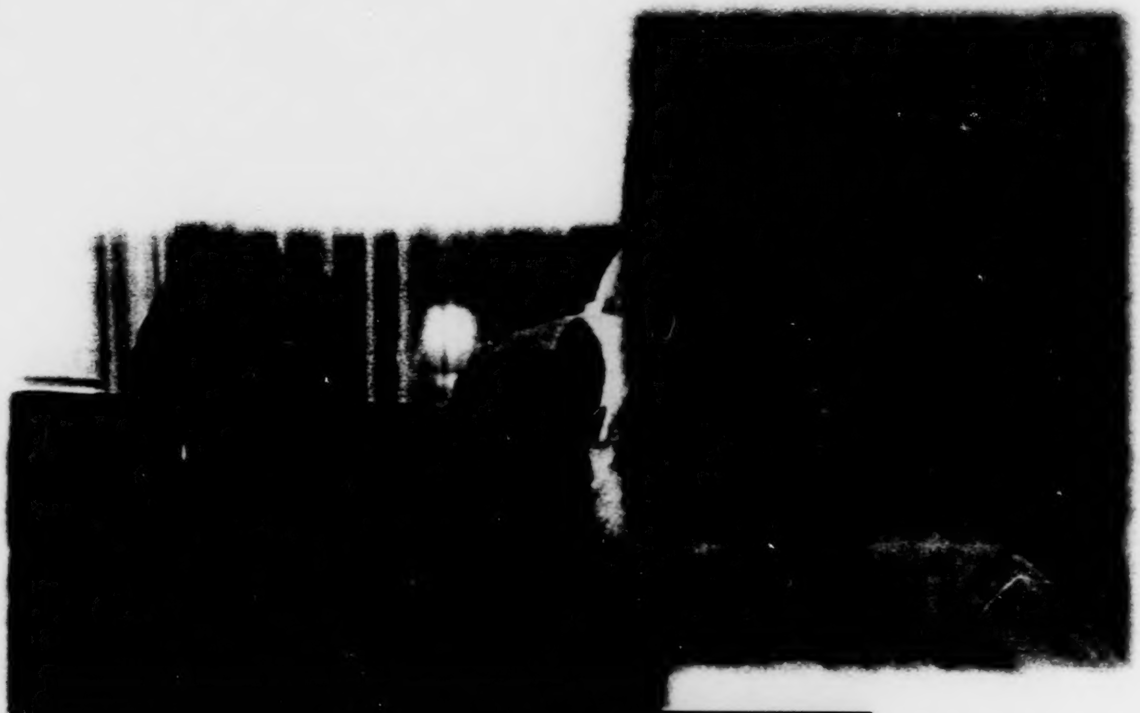
For subscription and advertising information, see page 74

Do you have: Cerebral Palsy • Multiple Sclerosis • Brain Injury • Spinal Cord Injury



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Circle #40

EDITOR'S DESK

Time for Taking Stock

February marks the mid-point in the school year, making it a perfect time to review your child's school progress. Check in with your child's educators to make sure they are following the school plan that you approved. If any changes have been made or need to be made, now is the time to discuss them. Although we are in the depths of winter, now is also the time to make plans for the next school year, as well as for the summer.

In "Darwin Goes to Camp," Darwin Carter's mother, Susanne, describes the emotions that are aroused when sending a child with a disability "away" for the first time. The positive contribution this experience made to his growth and development, as well as hers, belied all her initial fears. Next month we will include reader feedback on summer programs.

Susan Senator shares "The Secret to Happy Vacations" in her article by describing the planning that was necessary for her family's getaway. Many of the tips and suggestions that have worked for her family, which includes her son who is on the autistic spectrum, may be useful to other parents taking their clan "on the road."

You don't have to leave home to find fun and enjoyment in some everyday activities. "Bathtub Play" by the Let's Play! Project, describes some creative ideas to make bath time an opportunity for building skills while having fun. Let's Play! is a project of the Center for Assistive Technology at the State University of New York at Buffalo. The group, led by Susan Mistrett, has hands-on experience in adapting environments to encourage play for children with special needs, ages birth to 2. Though the group's focus is on early childhood, the play ideas that they have come up with can take the hassle out of bathing for any parent and child.

Early childhood—and beyond

The key element in any child's life is his or her family. We have always believed that the families of children with disabilities are real pioneers—having to find pathways for growth with few markers along the way and, sometimes, with little support. We often underestimate the energy and stamina this requires, and how much pressure these parents experience.

Recently, the Kelso family of Pennsylvania made national headlines when they left their son, who has cerebral palsy, at a hospital for children with disabilities, along with a note saying that they were no longer capable of caring for him. Naturally, there was shock at their abandoning their child in this way, and the opinion towards this family grew increasingly negative as it was revealed that the parents were financially secure. They should have been able to afford any services that were necessary.

Although no one should abandon a child in this fashion—or any other—the story unfolded, revealing problems that are well known to families who have children with disabilities. The Kelsos had been dedicated to the care of their child from birth. They were also leading advocates and leaders in their community. But what happened? No one can know what determines the actions of other people, but it is clear that money is not the real issue in the unending work and dedication of parents.

In December, Esther Schleifer had the privilege of interviewing the Crowley family of Pennington, N.J. Parents John and Aileen care for three young children, two of whom have been diagnosed with Pompe's disease, a potentially fatal illness. With great determination, faith, and optimism the family faces this challenge and we are proud to add them to the EXCEPTIONAL PARENT Hall of Fame. In Part One of this interview, the couple describe the source of their great optimism, which sustains everyone, including the various caretakers of their children; how they take care of the needs of their "well" child; the management of the treatment team; and the need for respite.

Special Report

Augmentative communication devices are making a significant difference in the lives of children. To expand on some of the points addressed in last year's special report on "Choosing and Using Augmentative Communication" (October, November and December 1999), we present the first of a series on "Can We Talk?: Parents' Perspectives on Augmentative and Alternative Communication." The article prepares parents for the assessment process and the roles and functions of the various professionals who evaluate a child.

Mark your calendars

EXCEPTIONAL PARENT is co-sponsor of the World Congress & Exposition on Disabilities (WCD), which will take place on November 10-12, 2000, in Atlanta, Georgia. Among the other sponsors of this informative event are United Cerebral Palsy, the Epilepsy Foundation, The Arc, Family Voices, the National Perinatal Association, and the National Down Syndrome Congress. We invite individuals with disabilities and their families, along with leading international experts in disability-related fields, to join us in this exchange of knowledge and experience. For more information, contact the WCD at: (877) 923-3976 or (201) 226-1446; Web site: http://www.wcdexpo.com.

Maxwell J. Schleifer, PhD
Editor-in-Chief

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Circle #37

SEARCH

Evaluating school districts

My husband is considering a job in another state. I have a 2-year-old who has cerebral palsy. Our local school district has a very good reputation for its special education services. How can I evaluate whether the schools in our future home state have good special education services?

—L.T., from the EP Web site

Respite care

I am a mother of two children with severe disabilities, and because my husband and I make too much money, we cannot get any help with the care of our children. Do you know any organizations that could help us get respite or nursing help in the home? We live in Michigan.

—Marcy, from the EP Web site

Prematurity and hydrocephalus

I am a mother of an infant who was born 14 weeks premature. He had all the expected problems, but I thought that even with the illnesses and frequent hospital stays all would be well. He is now 2. He has right hemiparesis (a definite weakness in the muscles on the right side). He still does not speak at age level and has begun to have complex partial seizures from minor brain damage. He also has hydrocephalus. I am looking for anyone in the same situation to give me some encouragement and advice.

—jhnylawdg, from the EP Web site

RESPONSE: *I am the mother of a child born 16 weeks premature with lots of complications, including hydrocephalus (shunted). At two years my son was nonverbal and had to be put back on oxygen. It seemed what the NICU nurses called "the roller coaster" was quite true—we went up, then down. We worked very hard and kept my son involved in early-intervention programs. We also accessed speech therapy through our insurance. The effort has paid off. My son is now 5, and although there continue to be challenges, such as having the shunt replaced when it broke, he is very verbal and in September entered · inclusive kindergarten with some support services.*

—pjstabile, from the EP Web site

EDITOR'S NOTE: *To better serve our readers and to take advantage of the power of the World Wide Web, EP will publish more of these "instant" Responds in future issues from our Web site (http://www.eparent.com). We will also continue to accept Responds via fax or regular mail (see below for information).*

CindyLift

I need information on the CindyLift. Where can I check into getting one to try it so we can determine if it would work for our family or not?

—V.M., from the EP Web site

continued on page 10

Search and Respond is an opportunity for our readers to exchange information about their practical experiences in meeting the everyday challenges of life with a child or adolescent who has a disability. We also expect parents to consult appropriate professionals.

Please indicate whether the letter is a Search or a Respond. If it is a Respond, be sure to note in which issue the original Search letter appeared. All responses are forwarded to the writers of the Search letters; some are published. Published letters may be edited for purposes of space and clarity. Please remember to include a phone number in the event that more information is required.

Write or fax: Search or Respond, *Exceptional Parent,* 555 Kinderkamack Rd., Oradell, NJ 07649-1517, (201) 634-6570 or visit Search and Respond on our Web Site: http://www.eparent.com. For information about specific disabilities, contact: the National Organization for Rare Disorders (NORD), 100 Rt. 37, PO Box 8923, New Fairfield, CT 06812; (800) 999-6673; (203) 746-6518 (http://www.NORD-RDB.com/~orphan). Also, see "National Resources for Specific Disabilities and Conditions" in *Exceptional Parent's* 1999 Resource Guide (January 1999).

The National Parent-to-Parent Support and Information Service (NPPSIS) is a not-for-profit service that keeps track of children with diagnosed and undiagnosed disabilities whose parents are looking for a match. Parents are matched with a "veteran parent," with an older child who has a similar condition and is willing to provide guidance and support. Contact: NPPSIS, P.O. Box 907, Blue Ridge, GA 30513; (800) 651-1151 (V/TTY) or (828) 494-5415; (828) 494-5414 (fax); E-mail: nppsis@elijay.com; Web site: http://www.nppsis.org.

EXCEPTIONAL PARENT

EDITORIAL MISSION

- *To reach out to mothers and fathers of children and young adults who have disabilities and special healthcare needs.*
- *To empower parents and professionals by providing practical information and emotional support.*
- *To appreciate that parents are the most important experts in the lives of their children.*
- *To energize parents and professionals.*
- *To share ideas and experiences so parents, professionals, people who have disabilities, and other advocates can learn from one another and better collaborate to serve all children and families.*

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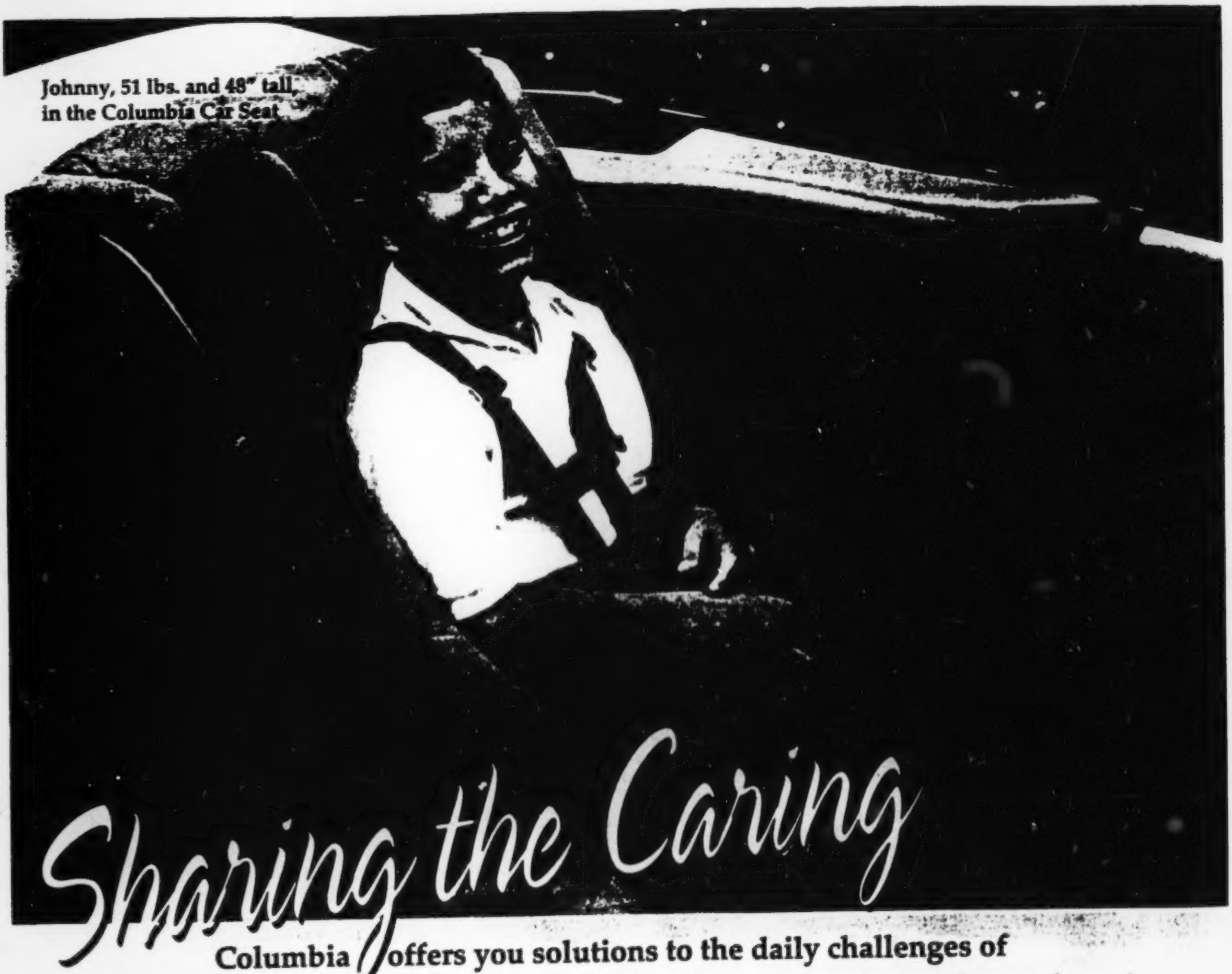

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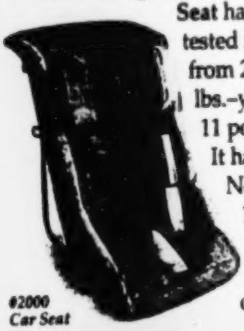

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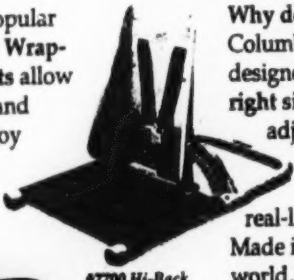

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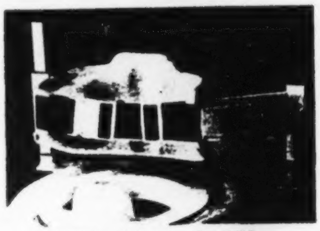

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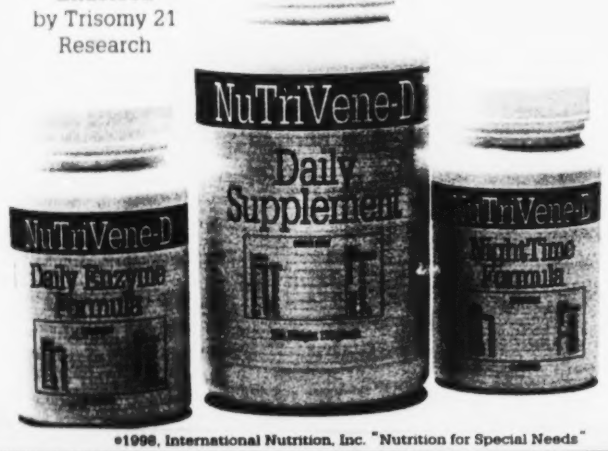

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Circle #35

SEARCH

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EDITOR'S NOTE: *The CindyLift is a device which enables one caregiver to transfer/lift a person with a disability from one place to another for toileting, bathing, dressing, etc. The current list price for the CindyLift is about $1600 including shipping and handling. They do not provide a trial period, but will accept returns and issue refunds. For a brochure with pictures and operating instructions, contact Creative Disability Solutions, 1685 James Winston Road, Oxford, NC 27565; phone: (919) 693-2796; or E-mail: cwinston@gloryroad.net).*

Bruxism and mouthing in autism

My 3-year-old son has autism. We are currently working with his autism specialist on oral motor therapy because he is constantly mouthing and chewing on objects. He loves it when I brush his teeth and the roof of his mouth. I have also provided him with teething toys. I am looking for ideas to help him stop grinding his teeth (bruxism) all the time and interested in techniques other parents use to deal with this and the chewing.

—Gina, from the EP Web site

Night paralysis

My typically developing 2-year-old son has had six episodes of "night paralysis" in the last eighteen months. He wakes up with a weak cry and his entire body is limp. His eyes are open but unfocused, and he does not respond to touch or sound. These episodes last up to ten minutes, after which he is lethargic, weak, and has difficulty controlling his muscles for tasks like swallowing or holding a cup. After sleeping the rest of the night, he wakes up in the morning with no apparent effects.

—Tamara, from the EP Web site

Dr. Feudtner: Ask your doctor for a referral to a good pediatric neurologist.

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Circle #42

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RESPOND

Mitochondrial metabolic disorder

B.B. (from the EP Web site: http://www.eparent.com) has a 2-year-old son with developmental delays and has been given a possible diagnosis of mitochondrial metabolic disorder (disorders that are characterized by decreased energy production by the cells of the body). B.B. would like to hear from anyone familiar with this.

I am a pediatric hematologist/oncologist by training and a parent of a son with Complex I and III deficiencies (deficiencies in chemicals that help cells produce the energy your body needs), which are mitochondria-based illnesses. Most practitioners feel that mitochondrial diseases are very rare. In fact, it is estimated that some type of mitochondrial disease affects nearly 1 in 4,000 births.

Some of the highlights of mitochondrial disease include the following:

1) First and foremost, people with identical defects in their metabolism will not have the same outcome.

2) There is currently no definitive cure, and the preliminary prognosis that doctors will give you is usually poor. (My son, however, was not supposed to live beyond 10 months. He celebrated his first birthday this past summer.)

3) Dealing with mitochondrial disease is like taking one of the world's biggest roller coaster rides.

4) I suggest that you check into the United Mitochondrial Disease Foundation (UMDF) for more information. They have a wonderful Web site with a lot of information (http://www.umdf.org/).

5) Despite how "rare" it is, keep in mind that you are not alone. Some researchers now believe that Parkinson's and Alzheimer's are mitochondria-based disorders.

6) There are only a few centers on the North American continent that deal with mitochondrial disease. The UMDF can help you find the one nearest you.

—Kenneth M. Hirsch, M.D., F.A.A.P., New Jersey; Web site: http://hirsch@rivendell-peds.com/special_needs.htm

EDITOR'S NOTE: *You can contact the UMDF at: P.O. Box 1151, Monroeville, PA 15146-1151; Voice: (412) 793-8077; Fax: (412) 793-6477; or E-mail: umdf@nb.net.*

In addition, Exceptional Parent published a three-part special report in 1997, which can be ordered by calling the EP Library at (800) 535-1910.

Infantile Spasms

T.L., Swanee, Georgia (October '99), has a 10-month-old daughter who has infantile spasms. She also has feeding problems, including gagging, vomiting, and a "pulling" motion that may or may not be a result of seizure activity. T.L. would like any input on the condition.

Our daughter (now age 20) had seizures that looked like gagging as a child. About 3 years ago she was diagnosed with esophageal reflux. I recommend that you consult with a gastrointestinal specialist as well as a pediatric neurologist.

—B.N., California

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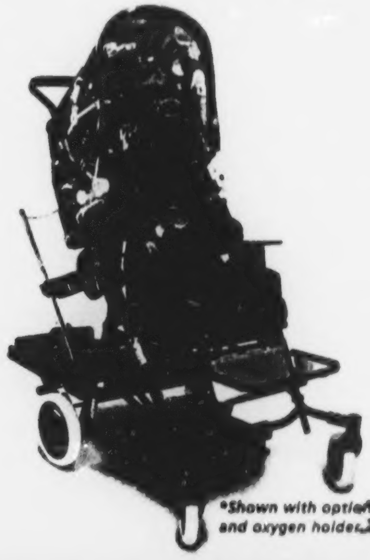
Ariel, 17 months old, 25 lbs



**Shown with optional ventilator tray, and oxygen holder.*

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Nominee for Exceptional People Awards

Brookes Y. Gordon of Lakekand, FL nominated her parents, Michael and Andrea for the Exceptional People Awards which appeared in the January issue of EP. Brookes, 16, has a rare neuromuscular disease called Werding-Ho[illegible] syndrome (characterized by progressive muscular weakness and atrophy). Brooks credits her parents with giving her the tools to meet her goals and desires. Brooks says, "Without having supportive parents and God, none of my desires and goals would have ever happened. This strength and determination comes from my parents always telling me that no matter what my physical limitations are, I can still achieve whatever I put my mind to."

Adaptive Windows™ tutorial

A Windows tutorial is now available on the Internet. The tutorial, Opening Windows 95™ was designed for adaptive technology users who are blind or have low vision. The tutorial is now available through the Columbia Lighthouse on three cassettes, including a workbook diskette. A large print version is also available. The taped tutorial provides step-by-step training in: taking phone messages in Notepad; organizing and updating information on the computer; using the functions of a new application; entering text, retrieving files, moving information from one application to another; and using shortcuts to streamline a Windows system. For more information, contact the Columbia Lighthouse at (202) 462-2900 x 3004, or (202) 462-4784; or by e-mail at tutorialsclb.org.

Top corporations unite to tackle employment problems

More than 20 national companies have come together to form a new consortium called Able to Work, to help expand employment opportunities for people with disabilities. The mission of Able to Work is to address the 71 percent unemployment rate of people with disabilities. These leading corporations have agreed to lead an advocacy effort among other corporate peers. The members of the Able to Work consortium represent a wide range of industries, all of whom have previously recruited and hired individuals with disabilities. The goal of the consortium is to increase employment opportunities by providing mentoring and direction to businesses throughout the country. Their Web site, http://www.Abletowork.org, provides member companies with an on-line venue for posting job openings, as well as serving as a resume-posting service, where companies can review the resumes of qualified applicants. Job seekers who do not have access to the Internet can send their resumes to NBDC, 201 I.U. Willets Rd., Albertson, NY 11501.

National Registry of Rehabilitation Technology Suppliers has a new Web site

The National Registry of Rehabilitative Technology Suppliers (NRRTS) has a new Web site. The site, located at http://www.nrrts.org, can help anyone who wants to locate a qualified professional who is knowledgeable about rehabilitative technology, such as wheelchairs, scooters, walkers, and other assistive devices. Features of the Web site include a fully searchable database to find NRRTS members, its Code of Ethics and Standards of Practice, a list of benefits to working with an NRRTS member, and a "Newsroom" for press releases and other important industry and professional information. NRRTS is dedicated to ensuring the provision of high-quality technology and related services to people with disabilities. All members of NRRTS meet specific professional membership requirements.

FDA establishes new Web site

The U.S. Food and Drug Administration (FDA) has established a new Web site designed to help consumers who are buying prescription drugs and medical products online. The purpose of the site is to increase public awareness about health, economic, and legal risks of online sales of prescription drugs and medical products. The site is located at http://www.fda.gov under the "Buying Medical Products Online" banners. The Web site also contains an electronic complaint form for consumers who believe they have encountered the illegal sale of drugs and medical products online.

Medtronic and NORD announce new program for people with spasticity

Medtronic Inc., and the National Organization for Rare Disorders (NORD) have announced the start of the Medtronic ITB™ Therapy Patient Assistance Program to help cover costs for those who need intrathecal baclofen injections for spasticity. The program helps eligible individuals obtain the Lioresal® intrathecal baclofen injection that is used in Medtronic ITB Therapy. The new Medtronic ITB Therapy Patient Assistance Program expands access to this effective treatment. Under the terms of the program, individuals whose federal, state, and private health insurance resources do not reimburse the drug costs for the therapy can apply for benefits that will

continued on page 20

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Dear Parents:

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We would be interested in looking into your child's birth if you had complications either during pregnancy, during delivery, or after delivery.

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Sincerely,

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Circle #38

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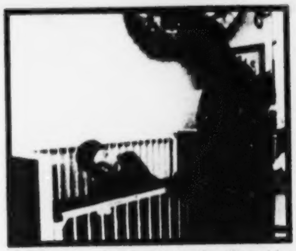
& Her Son Nicholas



The Stockton features full crib safety sides

Beds for children once they pass the crib stage are always an issue with parents... I can't begin to tell you how terrific the people at HARD Mfg. are. Mary Bias, the rep for the Indiana area told me she knew exactly what I wanted and needed for Nicholas. Thirty-days later the Stockton Bed arrived and it couldn't be more perfect! The Stockton comes in three sizes, with crib type rails, and a height adjustment up to 34"... saving my back! It even has a mounted IV pole for Nicholas' feeding pump. Mary had also suggested the white bed with a red outer footboard and yellow inner headboard...

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Thank You HARD!
Dianna Fitzgerald

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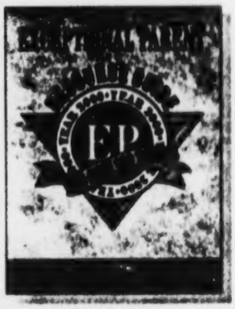

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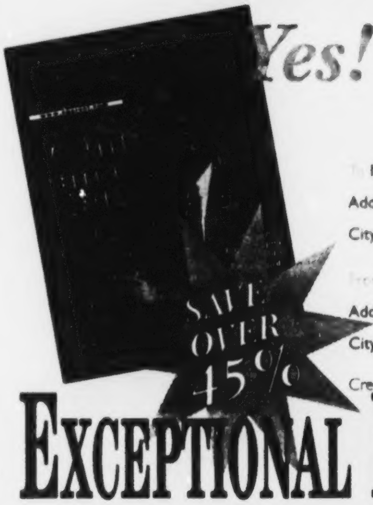

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Exceptional Parent

is the magazine for parents and professionals involved in the care and development of children and young adults with special needs, including Physical Disabilities, Developmental Disabilities, Mental Retardation, Autism, Epilepsy, Learning Disabilities, Perceptual Disabilities, Hearing Impairments, Vision Impairments, Emotional Problems, Chronic Illness.

Exceptional Parent's MISSION IS TO:

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practical guidance and support for parents, educators and professionals;

INFORM
parents and professionals about current and changing rights, laws and programs for children and young adults with disabilities, and their families;

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as a network, a forum for the exchange of ideas, experience and advice between parents, professionals and educators;

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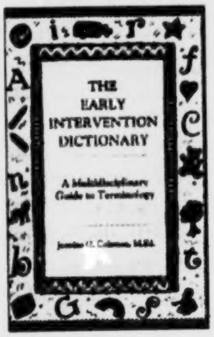
The Early Intervention Dictionary: A Multidisciplinary Guide To Terminology

By Jeanine G. Coleman, MEd

Published by: Woodbine House Publishing


THE EARLY INTERVENTION DICTIONARY
A Multidisciplinary Guide to Terminology
Jeanine G. Coleman, M.Ed.

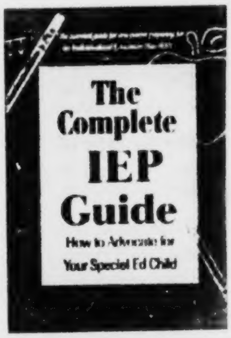
Becoming an active informed participant in your child's IEP is a process. Understanding the terms used by the professionals who care for your child is an important step in making sure the care is the best. That manual your child did not come with; well here it is. *The Early Intervention Dictionary*, by Jeanine G. Coleman, M.Ed.

Look up all those ABC terms come up regularly in your conferences with teachers, therapists, and doctors. From abductors, W-sitting, PDD, to growth charts it can all be found in this book, explained in family friendly terms. This is the book you will want with you at every meeting you attend. Become an equal player very fast with this great resource.

The Complete IEP Guide: How to Advocate for Your Special Ed Child

By Attorney Lawrence M. Siegel

Published by: Nolo.com Inc.



A source for information on individualized education plans(IEPs) you will not be able to proceed without is The Complete IEP Guide: How To Advocate for Your Special Ed Child, authored by attorney, Lawrence M. Siegel. This book guides you through the process of learning your rights, how to access the system, who has what roles and responsibilities, and where to obtain outside help. Last revised in June 1999, the information is very up-to-date. Chapters are broken down to go step by step, or to address your immediateconcerns. Start with identifying your child and his/her needs, requesting testing, how to obtain your child's records, and exploring available options. Sample forms and letters are supplied to guide you through the entire process. Step by step, you go through the process—from your options, to making your case. Learn how to write goal, objectives, and understanding measurable outcomes. As you gain knowledge and confidence in this process, you will no longer need to be one of those parents who arrives at meetings waiting to see what they will offer.

Instead, by the time your child's IEP meeting actually starts, everyone on your child's team will know what you want, why, how you hope it will be accomplished, and their role in the process. Should things not go well, this guide goes through the dispute process, Due Process, and filling complaints. There are resource lists with laws,what the IDEA (Individuals with Disabilities Act) says, recommended reading lists,and outside sources of guidance to offer additional help. This is one resource book you will use over and over as your child goes through school. Tips on things like starting an IEP binder, getting your issues on the agenda, drafting your child's IEP program, to sign or not sign, will become more comfortable as you learn more about the process. This is one book no "Special Ed" parent should be without. —*Joy Liebeskind*

Joy Liebeskind is the Director of the PATH Parent Resource Library which is part of the Connecticut statewide parent network.

Both of these titles are available through the EP Library (800) 535-1910.

The Early Intervention Dictionary can be ordered by using Item Code: WB030EI at a cost of $17.95 plus shipping and handling

The Complete IEP Guide can be ordered by using Item Code: NL001SE at a cost of $24.95 plus shipping and handling.

CALENDAR OF EVENTS

MARCH 3-5

Third Annual Council of Parent Attorneys and Advocates

Adam's Mark Hotel Houston, TX.

Topics will include an introduction to IEP basics and strategies and techniques to use in negotiating an IEP. For more information call: (954) 966-4489; Web site: http://www.copaa.net

MARCH 5-8

"A System of Care of Children's Mental Health: Expanding the Research Base"

13th Annual Research Conference.
Research and Training Center for
Children's Mental Health, Clearwater, FL

Topics will include current research and the relationship between child welfare and child mental health. For further information contact: (813) 974-4661 or (813) 974-4649.

MARCH 14-15

The First Tri-State Conference on Assistive and Augmentative Communication.

William Paterson University, Wayne, NJ.

The focus of this conference will be on technology for children in special education grades K-12 and higher. For registration information call: (973) 720-2491.

MARCH 18

Federation for Children with Special Needs Annual Conference—Mission Possible: Forging into our Future.

World Trade Center, Boston, Massachusetts

Topics discussed will include: sibling issues, assistive technology, meeting mental health needs on the IEP, and much more. For more information contact Federation for Children with Special Needs 1135 Tremont Street, Massachusetts 02120 Phone: (617) 236-7210; Web site: http://www.fcsn.org; or E-mail: fcsninfo@fcsninfo@ fcsn.org.

continued from page 14

be funded in full by Medtronic. NORD will administer the program, review completed applications, and award benefits based on applicants' financial need. Applications for the Medtronic ITB Therapy Patient Assistance Program can be obtained by calling NORD at (800) 999-6673, or (203) 746-6518. More information about Medtronic ITB Therapy is available on the Internet at http://www.itbtherapy.com.

Legislative update

On November 18, 1999, the conference report for the Work Incentives Improvement Act of 1999 was passed by the House of Representatives by an overwhelming bipartisan vote of 418 to 2. One day later, the Senate passed the act by a vote of 95 to 1. On December 17, 1999, President Clinton signed the Act into law. This new legislation will allow people with disabilities to retain their Medicare benefits longer than in the past and will remove the limits on the Medicaid buy-in option for workers with disabilities. The law also provides $250 million to states for demonstration programs to assess the health and financial benefits of providing Medicaid coverage to people whose condition has not yet deteriorated enough to prevent work, but who need healthcare to prevent deterioration. The Act is expected to enable more people with disabilities to participate in the workforce without fear of losing their Medicaid benefits.

New site offers service for viewing baby pictures

Parents can now share their pride and joy with the help of a new Internet-based service. The Internet site, http://www.babieshomepage.com, allows parents to create personalized Web sites with their child's pictures. This site is designed to provide distant family and friends with an easy way to exchange the latest images of their children over the Internet. Friends and relatives can visit the one location to see the latest pictures that are posted.

Easter Seals of southern California launches new Web site

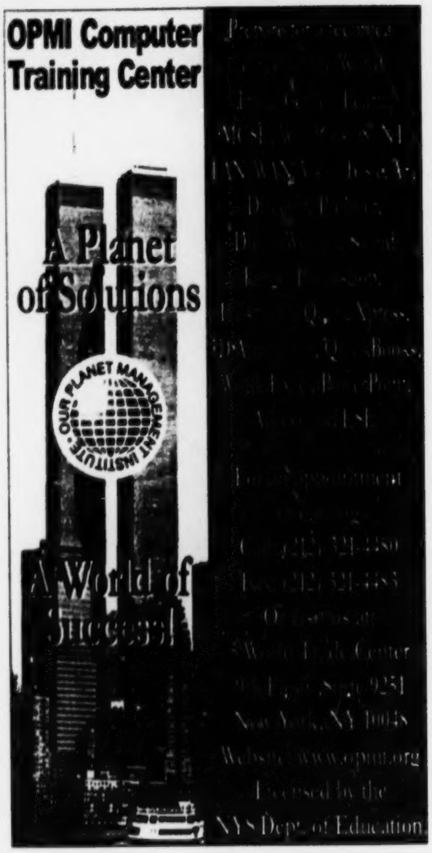
Easter Seals of southern California has launched a new Web site at http://www.essc .org. The new site features easy access to information about Easter Seals services for children and adults with disabilities that are available in southern California communities. With just a click of the mouse, Internet users can find descriptions and locations of Easter Seals programs that offer day care for children with disabilities, job training and placement for adults with disabilities, services for seniors, and more. The Web site offers another valuable community resource through its "Dear Lily" section, where Web surfers can get advice and referrals on disability-related topics and organizations. This new Web site serves as a valuable source of information for individuals seeking local, disability-related services and information. Easter Seals of southern California is a nonprofit organization that provides over 100 programs and services that help people with disabilities live with equality, dignity, and independence.

CORRECTIONS

December's 1999 *Organizational Spotlight*, Dystonia Medical Research Foundation, was mistakingly identified as Dystonia Medical Research Foundation of Canada.

On November 1999's *Children's Page*, "A Sign of Love" by Jared Petersen, we omitted to say that Jared's brother Craig has a visual impairment.

We regret both errors and apologize for any confusion they may have caused.



ATTENTION READERS!

June's theme is Technology in Education and Daily Living. Tell us about any technology, equipment, computer software or adaptive devices that you have found practical or useful in caring for your child.

Contact us at Attn:
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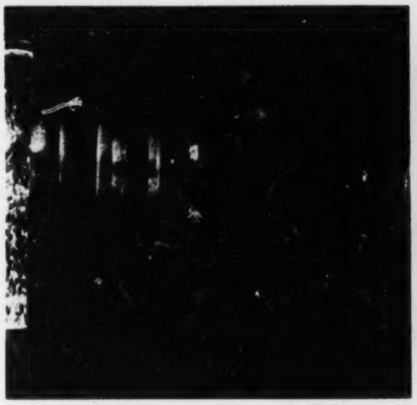

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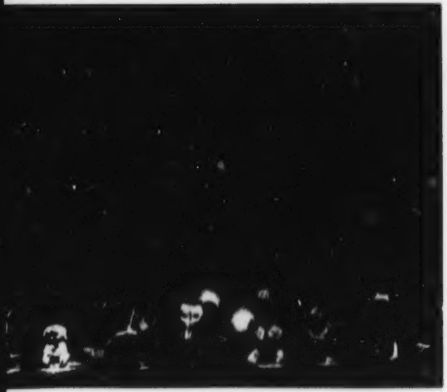

This innovative multimedia tool incorporates state-of-the-art technology to immerse users in an interactive environment of sound, light, and video projections. What's more, the Intelisense™ system allows therapists to customize *each session* to meet the varying and changing needs of *each client*.

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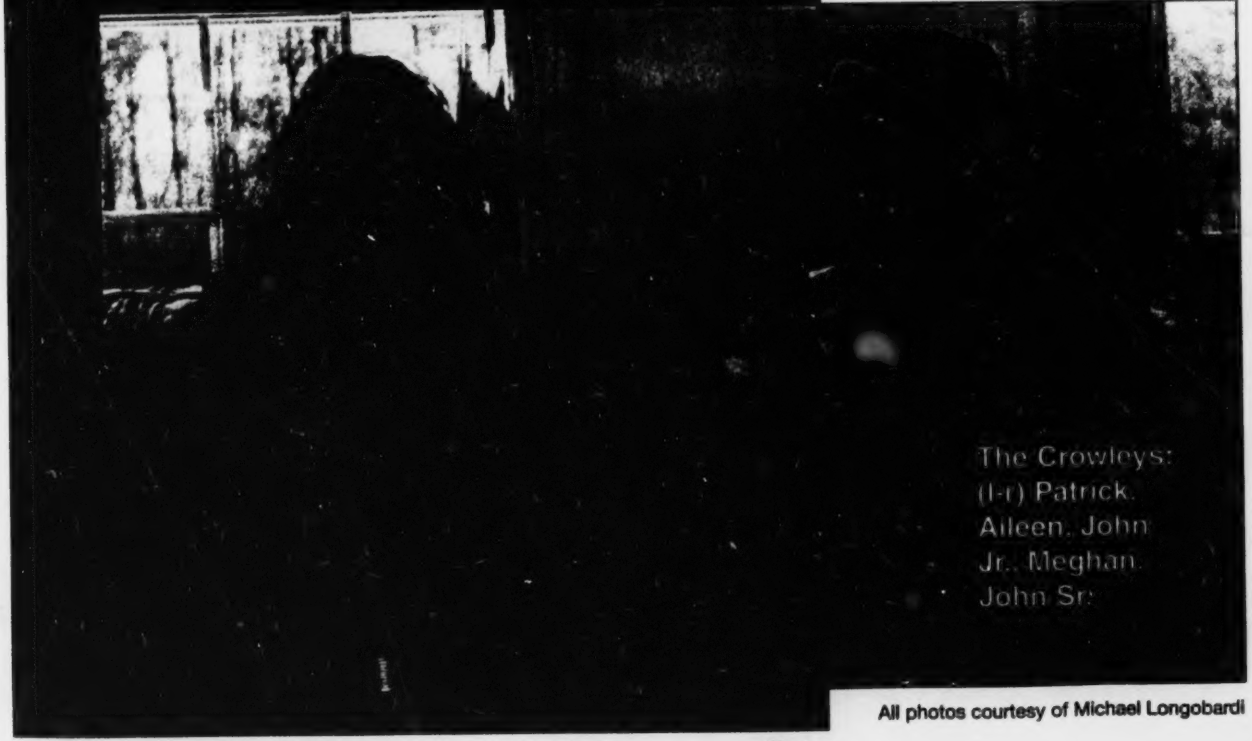
Circle #241

EP

EXCEPTIONAL PARENT'S HALL OF FAME 2000

John and Aileen Crowley are the parents of three children: John Jr., 4, Megan, 3, and Patrick, 18 months. This ordinarily busy household is complicated by the serious and rare illness Pompe's disease, that affects the younger two children. The Crowleys have done a remarkable job of managing the many challenges they face on a daily basis. They were willing to share their expertise with EP. We will present their experiences (in two parts) in their own words.

In this article, the Crowleys discuss their perspective on their children and their therapies, the coordination of the various professionals who are involved in their care, and the need for respite. They have also had the energy to create The Children's Pompe Foundation, which has contributed money to important research on Pompe's disease.



The Crowleys: (l-r) Patrick, Aileen, John Jr., Meghan, John Sr.

All photos courtesy of Michael Longobardi

Strength in the Face of Adversity

How one family meets the challenge of debilitating illness

STAYING POSITIVE

Raising three young children is a strenuous task under the best of circumstances. John and Aileen Crowley have two children who require 24-hour care for their survival. They live every day knowing that their children have a serious, potentially fatal disease, for which there is no cure. There are strangers in and out of their home all day. The enthusiasm and optimism of the Crowleys supports not only their family, but everyone who comes into contact with them.

JOHN CROWLEY: You get most of your strength from the kids. You can stay up until 2 in the morning working on foundation stuff and have to get up at 5:30AM the next day for work. You are tired and frustrated but you go into the bedroom and look into their eyes and realize time is your greatest enemy. That gives you all the determination you need in the world.

We give each other a lot of support. We have a lot of friends and family and a whole extended network of folks who have been usually supportive and helped pick us up when we are down. They reinforce all the positive aspects of what we are trying to do. We stay positive for ourselves, to keep us driving forward, but more so for the children. Their drive and spirit are so important in keeping them healthy. This will help them to have the will to fight and stay as strong as possible. We try to keep them as happy and pleasant as possible.

When Megan was first diagnosed, John and Aileen were immediately surrounded by an outpouring of support from friends and family.

JOHN: From the beginning, we shared the diagnosis and the doctors' comments with our families. Some of it was very explicitly stated, some of it was never said. We always felt that we would do everything in our power to change this. That was from literally within the first hour of the diagnosis, after the shock and the grief. Everybody in their own ways did everything they could to help contribute toward that effort. From Aileen's dad getting on a plane to go to California (where they then lived) within an hour, to my mother immediately getting on the Internet and typing in Pompe's disease, something we had never heard of, which helped us find out there are researchers out there and there was some hope.

JOHN: It's kind of instinctive, some people are enormously helpful. I had friends that I had not heard from in years who called to tell me their uncle is a pediatrician in Des Moines, if we needed to talk to anybody.

AILEEN CROWLEY: Some people just didn't know what to do. My younger brother, who lives in Chicago, said "I don't know what to do, what can I do to help?" People want to do something; they just don't know what.

TREATMENT PROGRAMS FOR THE CHILDREN

Megan and Patrick are both ventilator-dependent, use feeding tubes, and receive respiratory therapy. Megan has a teacher who comes to the Crowley's home. The children also receive care through the state's early-intervention program, Project Child.

AILEEN: Megan and Patrick get most of their therapies through Project Child. They've been wonderful. Some of the other families didn't even know about that. I told them you have to get in touch with this in your own state. They couldn't pay for a physical therapist and I told them they didn't have to, the state will do that for you. Megan is now considered "school-age," so the county pays for her schooling. She is of age now to be in preschool, and since she can't attend, they pay for a teacher at our home. She loves it. Having good teachers and therapists are key too. She loves her teacher, Miss Laura.

continued on page 24

continued from page 23

JOHN: Megan is the most intellectual and curious child you will ever meet and receptive—she started learning sign language when she was 14- or 15-months old. She knows hundreds of words now, and she uses it to communicate with us because of the muscle weakness in her mouth. We talk to her just as you would to any 3-year-old. In fact, she is a little more than precocious, and she talks back to us in sign language.

AILEEN: She's starting to use an attachment for her vent that helps her make sounds. We just got it two weeks ago, so she is just hearing her voice and being able to make sounds for the first time. It was nice. She's like a sponge; she can't learn enough. She's a good kid, and she just decided that her name isn't Megan anymore, it's Meg.

JOHN: Somebody taught her the sign for Meg, and she decided she wanted to be called Meg. She will correct you if you call her Megan. We held a fund raiser in New York a few weeks ago where we were fortunate to have Ben Vereen as a guest speaker. Up on stage, every time he would refer to her as Megan, she would turn around and do her sign for Meg.

She's a fighter, otherwise she wouldn't be alive. When Megan or Patrick are taken upstairs or downstairs, or to the car, their ventilators are disconnected for the brief time they are in transit. These lifesaving machines require frequent maintenance and surveillance.

AILEEN: She wears a ventilator while she sleeps, which forces air into her. When we transfer her, she doesn't tolerate it for very long, just to take her up and down the stairs or out to the car. Then we hook her back on. We have two ventilators, one upstairs, one down. They weigh forty pounds. We get them changed very often; you have to have a back-up in case one goes.

The respiratory therapist comes out every two to three weeks and he checks everything. One day Patrick was downstairs and the vent was not working; it just kept going out for whatever reason. Within two hours, they were there with a new ventilator. This is life and death.

SIBLINGS MATTER

John Crowley, Jr. is the big brother to his two younger siblings. It is challenging for a child to live with two siblings who are seriously ill. John and Aileen, however, have shared their wonderful, positive attitude with John Jr., who is not in the least uncertain about Megan and Patrick's future.

JOHN: I think Megan and Patrick are the center of all this. John is usually quite directly in the center.

AILEEN: He's old enough to know that Megan and Patrick are different. He knows everybody that was here this morning were for Megan and Patrick. He understands that and he deals with that in his own way. We try to make him feel special and make him stand out. He knows but he does not understand.

JOHN: John accepts that Megan and Patrick are sick and he has never known any different than that. He also believes, more than anyone else in this world, that they are going to be better. That is what we tell him, that they are going to grow up and they are going to be better, and doctors are working on special medicine. He never asks why. He just assumes they are going to grow up and they are going to be better, that they are going to go running with him and play ball with him, and swim with him.

AILEEN: We kept telling him we have done so much work on this foundation dinner in New York, it took a lot of both our time. I kept saying that Mommy has a meeting or daddy has to go somewhere. We say it's for a party for Megan and Patrick so we can get money for the doctors to get them a special medicine so they can run just like you and get rid of the machines. He was asking me the day after the fund raiser, "can we get rid of those 'sheens' now, mommy? Can we throw their 'sheens' away?" I said, "Oh no, not yet."

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ABOUT POMPE'S DISEASE AND THE CHILDREN'S POMPE FOUNDATION

Pompe's disease is a rare, muscular disorder. It is caused by a genetic defect preventing the body from producing a crucial enzyme called acid maltase. In healthy individuals, acid maltase breaks down sugars that are stored in the body's muscle cells. In Pompe's disease, the absence or insufficiency of acid maltase forces the body to continually store sugar in the muscle cells in the form of glycogen. Glycogen storage rapidly causes the muscle cells to deteriorate. This results in progressive weakening and deterioration of the muscles. Glycogen also accumulates in the liver, muscles, nerves, and heart, preventing them from functioning properly.

For children diagnosed at an early age, death from Pompe-related complications, usually respiratory or cardiac in nature, typically occurs before age five. Less severe forms of Pompe's disease affect older children and adults and cause weakness of the arms and legs and diminished ability to breathe.

The Children's Pompe Foundation, a not-for-profit foundation established in 1998 by the Crowleys and other parents, relatives, and friends of children with Pompe's disease, is dedicated to funding research and meeting the needs of children with Pompe's disease. The Children's Pompe Foundation has already raised more than $1 million, which has been distributed in the form of grants to various centers conducting research and trials for Pompe's disease. Currently, the treatment being studied is acid maltase enzyme replacement; gene therapy is also being evaluated for use in the future.

Dr. Frank Martiniuk is a researcher at NYU Medical Center in New York City, who has been studying Pompe's disease and enzyme replacement for nearly 25 years. Dr. Martiniuk said that a major concern in conducting research is generating awareness among the public. He went on to say, "I think that there is enough interest [in Pompe's disease] right now, because of people like the Crowleys. These diseases are relatively rare, and it takes people like them to get things going."

For more information, contact the Children's Pompe Foundation:
The Children's Pompe Foundation
66 Witherspoon Street, Suite 341
Princeton, NJ 08542
or call: (609) 924-7192 For credit card donations, call: (800) 316-0964
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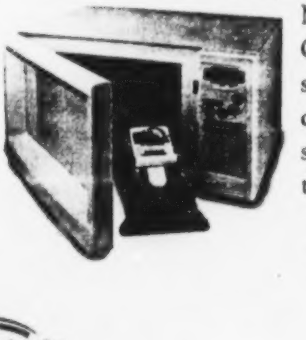

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Relaxing together, Patrick, Meg, and John take in some TV.

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JOHN: John Jr. doesn't have even the slightest bit of doubt in his mind as to whether science will work or whether it will work in time. He honestly, truly believes it's going to happen. John has his own needs like any child has, and that takes quite a bit of our time as well. But it's an effort, and you have to make sure it happens.

MANAGING THE HOME TREATMENT TEAM

The Crowleys host a virtual army of nurses, therapists, and other professionals throughout the day and night who all help care for Megan and Patrick.

AILEEN: They have physical therapists, speech therapists, and occupational therapists. Megan has a schoolteacher.

JOHN: The schoolteacher comes here.

AILEEN: We have nurses. Respiratory therapists.

JOHN: The occasional doctor who pays a house visit, which is very nice.

AILEEN: The medical supply company is here once a week, bringing all the medical supplies. The early intervention program staffers are building a special chair for Patrick, because he can't sit by himself anymore. They have built from cardboard, from scratch, a chair especially for him. We looked at chairs; they are close to $1,000.00.

RESPITE

Although John and Aileen maintain an unflagging optimism in their daily lives, they readily admit that they need to get away once in a while. The stresses involved in caring for Megan and Patrick, as well as working on the Children's Pompe Foundation, take their toll both physically and emotionally. Taking a break and relaxing allows them to function better and regain their stamina.

JOHN: We took our first vacation a couple of weeks ago since Megan was diagnosed a year and a half or two years ago. We went away for four days. To do that requires months of planning and we had two nurses here full time and two relatives and a nanny. We had a whole house of people to take care of the crew.

AILEEN: We are fortunate that we can do that, that we have people we can trust so that we can go away.

JOHN: It's always on your mind. We were able to relax knowing that we have such caring and quality people here. Even so, the kids are so inherently unstable that you are always concerned about them. We didn't find out until we got home, as we were flying back on the plane, that Megan was up with one of the nurses and her tracheotomy tube popped

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out. They couldn't get it back in. Megan turned blue, then purple, then black, and they did CPR. Sharon, who is the greatest nurse in the world, was crying when she told us this. She said, "I'm sorry. I thought I lost her."

So there is never a completely peaceful moment. Sometimes you need to step away from it, the environment, and you don't even realize it. The environment and the innate pressure here is quite a bit. Sometimes you need to get away, get out of the house, get a bite to eat.

AILEEN: We go out to dinner a lot, at least once a week, once the kids are asleep, the nurse is upstairs and all the kids are asleep. We will go out for dinner, get out of the house, which we need.

I also go out with John; I try to balance it out because John needs to get out of here. You can't keep a 4-year-old locked up in the house with two sick kids, so we really try to get him out. I am fortunate that I can trust the nurses, but I always feel that I am being pulled in both directions. Patrick and Megan are crying as I am walking out the front door with John, and if I stayed with them he would be crying because he wants me to go with him. It's very difficult balancing it all, and all I want to do is pick up Megan and Patrick and throw them in their car seats and have us all go out, but we can't do that without planning.

JOHN: You have to (take a break), no matter how determined you are, you will burn out. Sometimes that's hard, sometimes we will go weeks and weeks working hard, at work, with the family, and the foundation to the point where we don't even realize how tired we are getting. Sometimes it's friends or family that just have to say, you need to take a break, stop for a day.

It's hard because you don't want to stop, you feel every day you stop doing something is a day behind in getting the kids better. You just have to realize those days off recharge your energy and your enthusiasm and ultimately, your productivity and your output.

You are better with the kids too, you spend weeks and weeks on end, every day, tending to the kids. You get short with them, you get frustrated, and to have a day or two to be able to get refreshed, you are a better parent. **EP**

The Whole World in Her Hands

Stephanie was born with more obstacles to overcome than most people. Early in life, she was diagnosed with bilateral club foot, scoliosis, spina bifida, hydrocephalus, severe hearing loss, mental retardation, and seizure disorder. For her, these conditions were not obstacles, but challenges. She set herself a goal: to live as independently as possible. But she would need help.

At the age of 15 she came to Heartspring School. Her multidisciplinary team helped her identify specific objectives within her larger plan, then develop the skills to accomplish them. In the home setting she learned to prepare meals, wash her clothes and iron them, groom and dress herself … handle her own daily medical care. At school and out in the community she honed her communication skills, polished her ability to read body language and situational context. She learned how to shop for groceries with the help of picture cards. She took a job in a local restaurant, practiced a solid work ethic, and enjoyed the rewards of earning a living.

This past summer, when Stephanie graduated from Heartspring School at the age of 21, her certificate of completion meant far more than an ordinary diploma. It meant living more independently, caring for herself, holding a job … participating in the community and the world.

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EXCEPTIONAL PROFESSIONALS

Techno-Daycare

Nurse Janet Carroll is the EXCEPTIONAL PROFESSIONAL behind Nurses 'n Kids, Inc., daycare that provides a cost-effective alternative to extended hospital stays for children who are technology dependent.

Witnessing the smiles and giggles of the children seated at the little tables at Nurses 'n Kids, Inc., in Delaware, observers might think they were standing in any daycare center. Nurses 'n Kids, however, is a state-run pediatric daycare facility for children who are medically fragile.

Nurses 'n Kids was started by Janet Carroll, a pediatric nurse. Janet identified the need for such a program while working as a NICU (neonatal intensive care unit) nurse. Janet recalls her encounter with parents who were concerned over their daughter's pending discharge from the hospital. "The mother explained to me that the daycare center they had chosen for their daughter would not accept her because of her medical needs. Their daughter had been diagnosed with cerebral palsy and had several apneic episodes (the temporary cessation of breathing) while in the NICU, and therefore, would be going home on an apnea monitor. Both parents needed to work, so it was not an option for one of them to quit to take care of their child. That night, I went home and started thinking. There had to be options for this family and all other families who, unfortunately, would face similar crises."

How to make dreams come true

What Janet had in mind would not be simple, and would require major planning as well as backing from other sources, such as state government agencies. She did some research and found a program in Florida that provided the kind of high-level services she hoped to make available in Delaware. After visiting the facility there, she learned that it was made possible under legislation passed in Florida called Prescribed Pediatric Extended Care, or PPEC. Janet explains, "The purpose of PPEC was to reduce the financial burden associated with chronic illness; ease the loneliness of homebound isolation; and lower the number of hospital admissions for chronically ill children. Referrals to the facility came from hospitals and physicians."

Most children who receive services at PPEC centers require sophisticated technological interventions. Without this support, these children would have to remain hospitalized to receive the level of care they need, even though they are stable enough medically to be discharged. The costs associated with extended hospitalization can be devastating to a family. PPEC centers represent an alternative to this. Facilities are staffed by experienced pediatric nurses who can provide the prescribed technological care for their clients. In addition, prescribed therapies (physical, occupational, speech/oral, and motor) are provided on site by registered pediatric therapists. Centers

Happy faces at a Nurse 'n Kids center in Delaware.

support the children until they are healthy enough to enter mainstream child care.

According to Stephen Towne, RN, Director of Nursing at Nurses 'n Kids, shortly after the first PPEC Center was opened in the United States, independent evaluators found significant differences when healthcare expenditures of families with children receiving PPEC services were compared with control families—those whose children either remained hospitalized or were receiving in-home care. PPEC families also reported dramatically lower stress levels than those of the control families. Towne adds, "Results of this study support the cost effectiveness of PPEC."

Findings like these helped support PPEC as a worthwhile

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Community-based care for medically fragile children

It is estimated that about 1 million children in the United States have costly and disabling health conditions. 17,000 to 100,000of these children are technology dependent. For many years, children dependent on technology and medical intervention services lived in hospital settings for their entire lives. As a result of the prohibitive costs of hospitalization and long-term care, as well as concern for the quality of life of the children, community-based care programs are now being developed.

On average, costs of community-based services are one-third of those incurred through in-patient hospitalization. Community agencies have also found decreases in children's re-admissions to hospitals and decreases in family stress levels.

Establishing a program for families of children who are medically fragile can be both challenging and rewarding. Community service agencies must learn new skills and develop cooperative relationships with a wide variety of partners, especially family members. These agencies must also develop strategies that will ensure quality services at affordable costs.

The first step in establishing a program is to conduct community research regarding the needs of families (number of families, types of services desired, financial structure of families, etc.). It is imperative that family input into the design and structure of the program be solicited. For example, many families have reported that daycare-type services allow parents to regain their stamina during the day, so that they can meet the intense needs of their child when he or she is home.

Once plans for a program are in place, the developer of the program must check state licensing requirements. In some states, only licensed personnel (e.g., nurses) are permitted to administer medications or perform health-related tasks, whereas other states have made allowances under their health services code to allow trained respite providers to administer medications and perform some basic health-related tasks.

-Adapted from the ARCH Factsheet number 11, published by ARCH National Respite Network. For more information, contact ARCH National Resource Center, 800 Eastowne Dr., Ste. 105, Chapel Hill, NC 27514; phone: (919) 490-5577; fax: (919) 490-4905.

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endeavor. Working with Delaware's Department of Health and Social Services, Janet enabled similar PPEC laws to be introduced into the state legislature. Janet was subsequently asked to help develop the rules and regulations for PPEC in Delaware, paving the way for her dream to become reality. In 1988, Nurses 'n Kids opened its doors and has been growing ever since. Janet recalls, "In May 1990, the facility obtained a contract with Medicaid for PPEC, and soon the first expansion took place to accommodate the numbers of clients that needed PPEC services."

Above: Janet Carroll, founder of Nurses 'n kids, meets with staff members. Right: A child enjoys a game at Nurses 'n Kids.

Putting all the pieces together

As a family-centered program, Nurses 'n Kids is always trying to meet family needs. Dealing with insurance companies is not an easy task, so Nurses 'n Kids developed special procedure codes to facilitate handling insurance claims. Charges for Nurses 'n Kids services are determined by the level of care and number of therapies a child requires. Billing is done on a per diem basis, but third-party payers can be billed monthly or weekly.

...PARENTS OF A CHILD RECEIVING NURSES 'N KIDS SERVICES CAN ASSUME A MORE NORMAL LIFESTYLE OR RETURN TO WORK KNOWING THAT THEIR CHILD IS RECEIVING EXPERT AND LOVING CARE.

In addition to providing care, Nurses 'n Kids also provides parent training. Parents of children who attend receive instruction in both technological skills and child care. With this training, parents feel more confident of their ability to manage their child's medical needs. In addition, parents of a child receiving Nurses 'n Kids services can assume a more normal lifestyle or return to work knowing that their child is receiving expert and loving care.

When parents were uncomfortable transporting their children to the facility, Janet and the program's Managing Director, Gina McCoy, responded by initiating Nurses 'n Kids Transportation, Inc. Currently, the program transports PPEC clients throughout Delaware in specially equipped vans with a trained driver and nurse. According to Janet, "Parents began to ask if Nurses 'n Kids could provide home care so that they would not have to deal with so many agencies." Nurses 'n Kids at Home, Inc., providing standard and critical in-home care, was then born.

Janet sums up, "I had a dream many years ago, and as we strive to become a full service pediatric agency to provide and maintain a high level of excellence of care, we all believe in that dream. Each child is special." **EP**

To learn more about PPEC, or how to initiate the legislative proceedings to start a PPEC center in your state, call Janet Carroll, founder of Nurses 'n Kids, Inc., at: (302) 323-1436.

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PLACING YOUR CHILD WITH A DISABILITY IN DAYCARE:

Matching your child's needs with the right facility

By Patricia Durham, RN C. BSN

In 1990 the ADA (Americans with Disabilities Act) was passed. This law mandates accessibility for people with disabilities, including children. Some of the main issues of the ADA address architechtural barriers. Buildings built since 1990 must meet certain guidelines such as having wider doors for wheelchairs, accessible parking spaces and curb cuts.

Another area it addresses is public and private accessibility of services for people with disabilities. Thanks to this law, all children may attend daycare, sports events, concerts and other "normal" kid activities.

My daughter, Savannah Durham, who has chromsome18q- (a rare chromosomal deletion), was born in 1988, before the ADA. Savannah is legally blind, nonverbal, and nonambulatory. She has a congenital heart defect and a seizure disorder. She also has had respiratory and intestinal problems. Otherwise, Savannah is just like any other child. As a single working mother, I realized that daycare was essential. I took Savannah to several daycare centers, trying to get her enrolled. Interviews for enrollment were not always positive. As soon as Savannah's medical status and special needs were discussed, we were often turned away with phrases like, "We just can't handle her here," or "Because she takes extra time there will be extra cost," and "What will the other children think if we took care of her?"

After several unsuccessful attempts, I used a different approach. I did not phone and give information about Savannah and her disabilities. Instead, I dressed Savannah up, and we went to the daycare center in person. I introduced her by saying, "Here is Savannah! She is great and so easy to care for!" Instead of saying, "She is in a wheelchair and can't walk," I said, "In her wheelchair she is mobile enough to go outside and interact with the other kids." Instead of saying, "She doesn't talk," I said, "Savannah claps her hands to get your attention." I then followed with a thorough review of her nonverbal cues for the caregiver in charge of her.

If the daycare manager still seemed skeptical, I offered a two-week trial period. I knew that if they had the opportunity to work with Savannah, they would accept her. A trial period allows the center to work with your child and gives them the opportunity to view him or her as a child, not a disability. This benefits the parent also, because it provides you with the opportunity to observe and make an informed decision on whether that particular daycare center is right for your child.

Savannah (center), with her two primary caregivers, Kim Sparks and Megan Taylor.

Day Care Work Sheet

Name ______________________

Date ______________________

Parent Comments ______________________

Time	Activity	Meals/Snacks	Diaper Changes			Leg Braces		
			wet	b.m.	dry	on	off	
6:00								
7:00								
8:00								
9:00								
10:00								
11:00								
12:00								
13:00								
14:00								
15:00								
16:00								
17:00								

Teacher Comments ______________________

Of course, if you get an outright "No, we don't take kids like that here," you have a few options. First, try explaining to the daycare center about the ADA law, and how your child has a right to be served. Second, try a collaborative approach with open communication. Most of the time, the center will be willing to work with you. It is more difficult when an adversarial relationship exists.

Sometimes, however, assertiveness is called for as a last resort. You can contact your local legal group for people with disabilities. These advocacy groups are often free and offer advice on these issues. *(See The Protection & Advocacy System at the end of this article.)*

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Patricia Durham, and her daughter, Savannah.

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Remember, perseverance pays off. Developing a true, working relationship takes time. What matters is that both the daycare center and parents are willing to work things out with open communication.

CAREGIVER STRATEGIES: TRAINING FOR DAYCARE STAFF

Most children with disabilities utilize a host of experts in their everyday lives (e.g., physical therapy, speech therapy, occupational therapy, case managers, in-home trainers and others). Ask some of these specialists to help train the daycare staff. Most of the apprehension felt by the daycare center is related to a feeling of not knowing how to adequately care for a child with disabilities. For example, I scheduled Savannah's speech therapist to go to the daycare twice a week, to feed her lunch, and to assist the daycare staff with any feeding concerns. You may want the physical therapist to instruct the staff on different ways of positioning your child and using good body mechanics to prevent muscle strain. Demonstrating to the staff how you care for your child is also helpful. By observing how you position your child

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CHILD CARE OPTIONS FOR WORKING MOTHERS

REGULAR DAYCARE—Where your child would be if they were nondisabled.

EXTENDED FAMILY—For emergencies. Many grandparents also work.

RESPITE SERVICES—From your local state or county Department of Human Services Division of Developmental Disabilities, or other community service. This can include one to two hours coverage or several days for vacation. Call your insurance carrier and find out how you are covered for respite. ***TIP:*** Fill out the forms and try the service before you really need it. Realize that most respite programs have waiting lists.

HOME AND COMMUNITY SERVICE—A program through Mental Health and Mental Retardation, where a person (in-home trainer) comes to your home and works with your child on activities of daily living such as feeding, bathing, playing, etc. This type of service usually has an extremely long waiting list.

COLLEGE STUDENTS—
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Particularly students who are majoring in speech, occupational, or physical therapy. Others may include special education or human services majors. Post an advertisement at your local college. Some majors are required to volunteer a cetain number of hours working with people with disabilities.

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and how you communicate, they pick up helpful information. Of course, the daycare staff should already have formal training in CPR and first-aid.

If your child is fortunate enough to have an in-home trainer or other support person caring for them, send that person to the daycare center to offer help during peak times.

Savannah is in a regular room with her peers. Initially, the daycare center had wanted to place her in the infant room. I disagreed, knowing how important age-appropriate interactions are to all children.

CLASSMATES

When children first meet Savannah, they are curious. I answer questions freely to help them understand her condition. Many children like "helping" Savannah play. She loves the attention she receives from the other children.

COMMUNICATION

Communication between the caregiver and parent is essential. Savannah is nonverbal and cannot relay information; therefore, communication between her caregiver and me was critical. I would drop Savannah off at 6:00 am and pick her up at 4:00 pm During the day, she may have had up to three different caregivers. I was frustrated when I asked the afternoon caregiver how the morning was, and she did not know. A simple solution was to use a clipboard to record her progress during the day.

I found that a checklist was easier, because most caregivers do not like having to write down the entire day's events. Notes to certain teachers can also be written on the clipboard.

Finding the right daycare center for your child may be challenging, but it will give you peace of mind, and your child an enjoyable and caring environment.

Patricia Durham, RN C. BSN, is a registered nurse and Savannah's mother. They live in Lubbock, Texas.

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For more information, contact:

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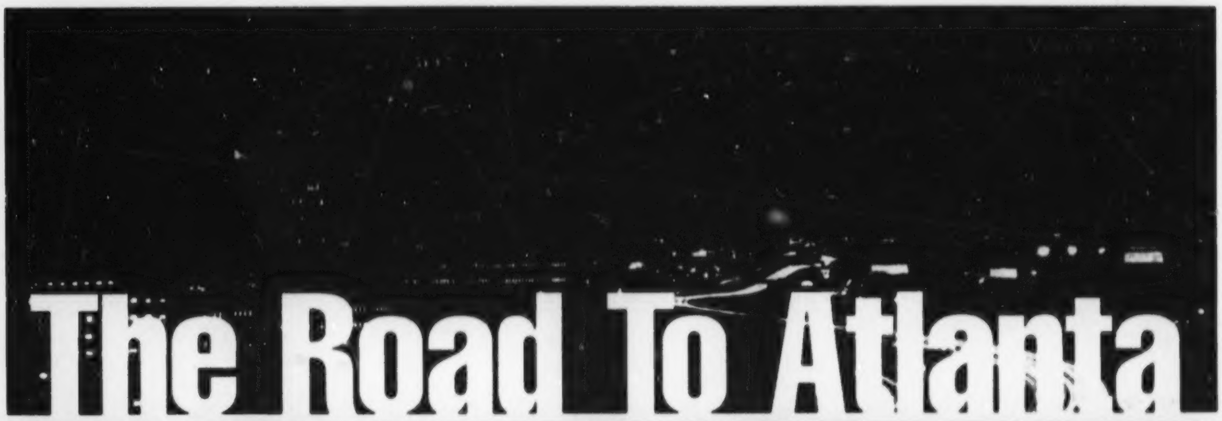

The Road To Atlanta

NOVEMBER 10-12 2000 WORLD CONGRESS & EXPOSITION ON DISABILITIES

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World Congress Vision Becomes Clear as Leaders Shape Program

The road to Atlanta is paved with...cooperation, enthusiasm, and commitment. As the old year, century, and such prepared to turn, the advisory/steering committee of the World Congress & Exposition on Disabilities (WCD) met for the first time. WCD, set to take place November 10 to 12 at the Georgia International Convention Center in Atlanta, has a unique, multifaceted orientation: uniting personal, family, and professional concerns and information in one conference on disabilities. It promises to combine the educational aspects of an international professional conference, the advocacy and "how to" of a families forum, and the in-depth product and service information of a trade exhibition.

Working together

The 19-member advisory/steering committee—including physicians, parents, educators, association leaders, advocates, and government office representatives—reflects WCD's unified approach. Its goal is a three-track agenda compatible with the educational interests of individuals with disabilities, their families and caregivers, and both the educators and healthcare professionals who work with them.

During the day-long meeting to hammer out both approach and detail, physicians, opinion leaders, special education professionals, and caregivers worked hand-in-hand to create a uniquely powerful education event with topics relevant to each other, yet positioned to offer value to each group. Professionals in the room listened attentively to parents, advocates to policy makers, caregivers to practitioners. They not only agreed on the importance of others' points and perspectives, but also bought into their inclusion as critical agenda items.

Joe Valenzano—Conference Director and CEO, President and Publisher of Exceptional Parent magazine—delighted in the committee's first efforts. "Never before in my 25 years in the healthcare industry have I witnessed what I saw there. Everyone approached this challenging task with enthusiasm, commitment, and a belief in the value of what we are trying to accomplish. This is unique, especially in a group so talented and with such diverse backgrounds—and where many had not even met until that day."

A work in progress

For parents and other caregivers, WCD will present exciting new medical developments, as well as information on critical family and community issues. Workshops and seminars will increase skills in such areas as dealing with insurance companies, building advocacy or support groups, contacting and working with both government officials and the media, and using the Internet for information and advocacy. Special pavilions are planned for vision and dental screening and employment contacts for people with disabilities.

For professionals, a key element will be opportunities to meet and share information, ideas and effective practices with colleagues from around the world. With CME and CEU credits being offered, there will be workshops in advocacy, seminars in office and clinic management, networking with government officials, and identification of important professional and family resources.

Both formal and informal gatherings will encourage all participants to share ideas, approaches, and information. Meanwhile, an exhibition hall of 200 vendors will be open for perusal, discussion, and ideas for the future.

For more information about the
World Congress on Disabilities,
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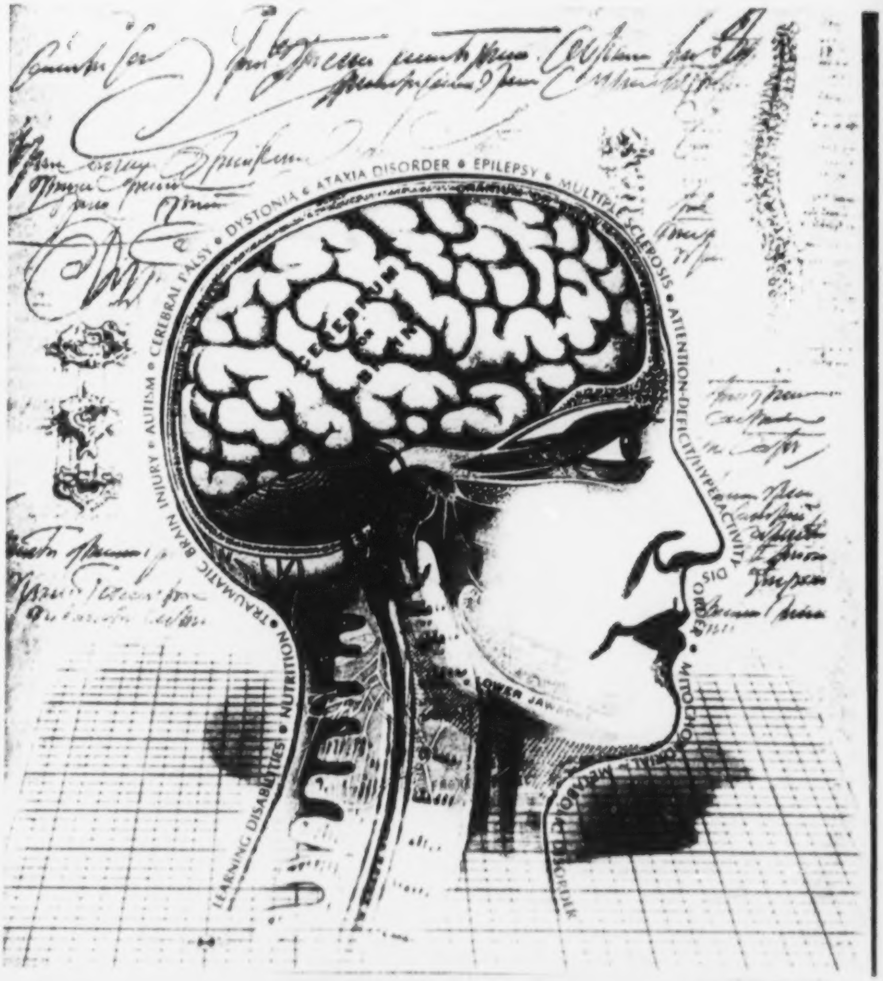
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Circle #31

Exposition on Disabilities

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Exceptional Parent Magazine and H.A. Bruno, LLC invite families of people with disabilities and professionals from the fields of healthcare and education from across the United States, Canada and around the world to share information, strategies, experiences, ideas and innovations.

WORLD CONGRESS & EXPOSITION ON DISABILITIES
WCD

A World-Class Weekend

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For Families and Caregivers: Experienced parents and professionals share first-hand, hands-on and first-person strategies and techniques for planning and problem solving in the home, the family, the community and the world at large. 400 associations are invited to share programs, projects and advocacy ideas.
Agenda items: insurance, schools, recreation, estate-planning, health care providers, employment, assessibility, technology, and many more.

For Physicians, Physical Therapists, Occupational Therapists and Educators: International experts discuss movement and brain disorders in symposia, lecture and workshop settings. Emory University's School of Medicine provides CME and CEU credits and administers a call for papers. Professional associations are also invited.
Agenda items: ataxias, spasticity, Tourette, Parkinson's, epilepsy, AD/HD, newborn screening for inborn metabolic errors, mitochondrial diseases, infant nutrition, learning disabilities, and many more.

For Those with Disabilities: Opportunities for information and hands-on introductions to the latest innovations in technology, health care, fun and advocacy.
Agenda items: Free dental and vision screening, hands-on workshops in technology and educational software, sports and recreation pavilion, Career Fair featuring live interviews with major corporations, the best toys, games and videos for fun and educational use and many more.

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WORLD CONGRESS & EXPOSITION ON DISABILITIES STEERING/ADVISORY COMMITTEE

Various leaders from different corners of the disabilities field gathered recently in Rockville, MD to help crystallize a vision that has been in the works for more than two years. This elite group of individuals included parents, direct service providers, association executives, physicians and educators as well as government health-care professionals.

The all-day session resulted in the creation of a cross-educational program that will bring together people with disabilities, their families, direct service providers, educators and healthcare professionals. It was, according to those in attendance, precedent-setting.

"I honestly believe we accomplished more than I could have hoped for at this first gathering of the people we very much are relying upon to help us create this dream," said Joe Valenzano, CEO, President and Publisher of Exceptional Parent magazine and Conference Director of WCD.

The WCD Steering/Advisory Committee includes: **Judy Blazer**, We Move; **Dr. Joe Botti**, National Perinatal Association; **Dr. Mitchell Brin**, Mt. Sinai, We Move and the Movement Disorders Society; **Cindy Brownstein**, Epilepsy Foundation; **Victor Erickson**, Council for Exceptional Children; **Dr. Steve Groft**, Office of Rare Diseases, National Institutes of Health; **Dave Harmon**, MetLife; **Nancy Harris**, Harris Consultants ; **George Jesien**, Ph.D., American Association of University Affiliated Programs for People with Developmental Disabilities; **Julie Keys**, Family Voices; **Valerie Levitan**, Ph. D., Dystonia Medical Research Foundation; **Dr. Merle McPherson**, Health Resources and Services Administration; **Suzanne Mintz**, National Family Caregivers Association; **Dr. Diane Moddeman**, Canadian Pediatric Society; **Frank Murphy**, National Down Syndrome Congress; **Dr. Rick Rader**, Morton J. Kent Rehabilitation Center; **Esther Sherberger**, Parent to Parent of Georgia; **Sheila Sorkin**, National Perinatal Association; **Lynda Voyles**, Council for Exceptional Children; and **Dr. Phil Ziring**, American Academy of Pediatrics.

Please send me information on the World Congress & Exposition on Disabilities, November 10- 12, 2000 at the Georgia International Convention Center in Atlanta

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Childcare for Children with Special Needs

by Shelli Yesenko

The Americans with Disabilities Act requires all childcare programs to make reasonable efforts to accommodate children with disabilities, unless doing so would be excessively difficult or expensive or would change the basic nature of the childcare program. While many childcare centers are willing to accept children with special needs, parents need to make sure that these facilities are staffed and equipped appropriately to provide the range and level of care their child with special needs requires. Following are some suggested questions and general guidelines on the type of responses parents should be looking for from childcare providers. It may also be helpful to discuss the child's specific needs with their physicians and therapists so that questions can be tailored to address those areas.

Q Has your center served other children with special needs?

A A "no" answer should not immediately eliminate the childcare center as a resource, but should open the door for questions about its capability to provide the extent of care and attention the child might require. A "yes" answer should lead to discussion on how the special needs of the other children are or have been accommodated, and the level of experience and/or training the staff has in this area.

Q Do you feel your childcare center has sufficient staff to serve children with special needs?

A The staff-to-child ratio at the center is an important gauge. A center with only minimum staffing may have difficulty providing the extra care required by some children with special needs.

Q Are therapy services (such as speech, occupational, or physical therapy) an integral part of the program, or can these services be provided on-site by an outside resource?

A Some childcare programs integrate these services or allow outside resources to augment their regular program.

Q Is the staff who will be caring for my child willing to talk with my child's pediatrician or other specialists?

A It is important that the caregivers for a child with special needs communicate with each other and coordinate their caregiving strategy.

Q Does your childcare center have access to the types of specialized equipment my child requires?

A In most cases, the answer will be "no." In this instance, the parents and caregivers will need to work together to secure any specialized equipment or adapt the equipment already available. The family's insurance company or another resource may provide the equipment. An important follow-up question to ask is whether the staff is willing to be trained in how to use and maintain equipment properly.

Q Are progress notes kept on each child?

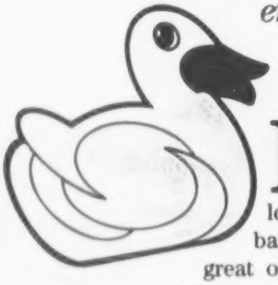
A If regular feedback is important to you, work with the childcare staff to develop a mutually acceptable system for tracking your child's activities during the day. Finding the right childcare program does not end at the point of enrollment. Caring, experienced childcare providers know that ongoing communication between parents and providers is one of the most important factors in ensuring the health and happiness of your child.

Shelli Yesenko is the Program Director for Within My World at PACT: Helping Children with Special Needs, Inc. PACT is affiliated with the Kennedy Krieger Institute, Baltimore, MD, and is a non profit children's organization providing early-intervention services and specialized childcare programs.

Creating Play Environments

by The Let's Play! Project

The Let's Play! Project specializes in creating and adapting environments to enable children to play. While their area of focus is on young children (ages birth to 2) many of these bath-time activities can be useful and enjoyable for older children as well. It's all good, clean fun!



For children who already love the water, bath time is a great opportunity to increase their experiences with movement, learning, and imagination. For children who are not enthusiastic about bath time, play activities may diminish anxiety, especially if they feel "in control" of the activities.

Of course, it is essential that the child be safe in the water before he or she plays. There are a number of commercially available tub seats for young children. For older children who require supports, a bath seat may need to be ordered from a specialty catalog.

Once a child is properly supported, let the games begin!!!! Water is a wonderful sensory medium as it "responds" to virtually any movement. For the young child, it may be fun to just splash by moving arms and legs in the water. The resistance of the water is a good way to increase muscle strength and the feedback your child will get is a "splash."

Bath time is a wonderful time to play with your child!

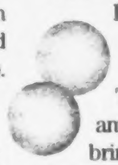
Games to play/materials to use

- Naming body parts is a classic tub game. Use a wash cloth, a bar of soap, a paintbrush, or foam soap to wash the body part your child has indicated. You can also put the child in charge of washing as you name the part to be washed. This can be a fun turn-taking game. With a paintbrush, your child can "paint" the tub with his or her body.
- Certain materials encourage water play: sponges for squeezing and wringing with two hands, cups to fill up and dump, or two cups to pour water back and forth between them and "mix" the water. Turkey basters are great for squeezing, and funnels are also interesting to pour water into and watch it come out.
- Consider using empty dish liquid bottles or spray bottles to squirt water. Have an older child squirt the water into an empty margarine container floating on the surface to "sink the ship," or aim at his or her toes.
- Another game which encourages eyes and hands to work together is using a fish net or ladle to scoop floating objects (plastic fish, ping-pong balls, etc.) out of the water. Also try putting a few ice cubes in the bath water. This will allow the child to

Bathtub Play

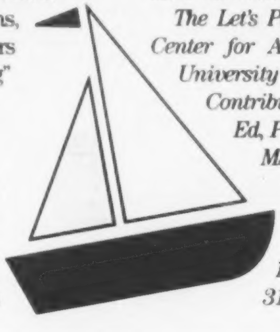
experiment with different temperatures and watch the ice cubes melt.

- Using foam soap or shaving cream at bath time can be fun. A child can use both hands to rub it on his/her body, the sides of the tub, and even on the walls (surfaces dependent). Try making handprints in the shaving cream using a paintbrush or a finger.
- Tub blocks, available in most toy stores, are fun in the water. When wet, these toys stick to shiny tub and wall surfaces. A younger child can catch the blocks as they float in the tub or push them down into the water and watch them pop up! He or she can also knock them down with his/her hand, a paintbrush or a spray bottle. An older child may enjoy creating a picture.
- To promote creative play scenarios, consider bringing small action figures and/or animals into the tub. By combining the figures with other tub toys, a variety of imaginative play scenes can be created (e.g. people on a boat, in a swimming pool, or even in a flood). Bringing a waterproof doll into the tub and washing the baby is also an imaginary play favorite. Tub time is wonderful for amateur cooks too. Consider bringing strainers, spoons, pots, and empty spice containers into the tub for a fun "cooking" experience.



Note...

The experiences described above do not have to be limited to the tub. In nice weather, many of these play activities can be done in a small wading pool. If you are really brave, you can create an indoor beach. Fill up a small pool in the house and put a shower curtain underneath it to protect the floor. Next to the water, set up a large cardboard box filled with dry beans or pasta for the "sand". Many of the water activities can also be done in the "sand." **EP**



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The Let's Play! Project is through the Center for Assistive Technology, State University of New York at Buffalo, NY. Contributors: Susan Mistrett, MS, Ed, Project Director; Amy Goetz, MS, OTR/L, Project Evaluator; Shelly J. Lane, PhD, OTR/L, FAOTA. 515 Kimball Tower, Buffalo, NY 14214; phone: (716) 829-3141; fax (716) 829-3217.

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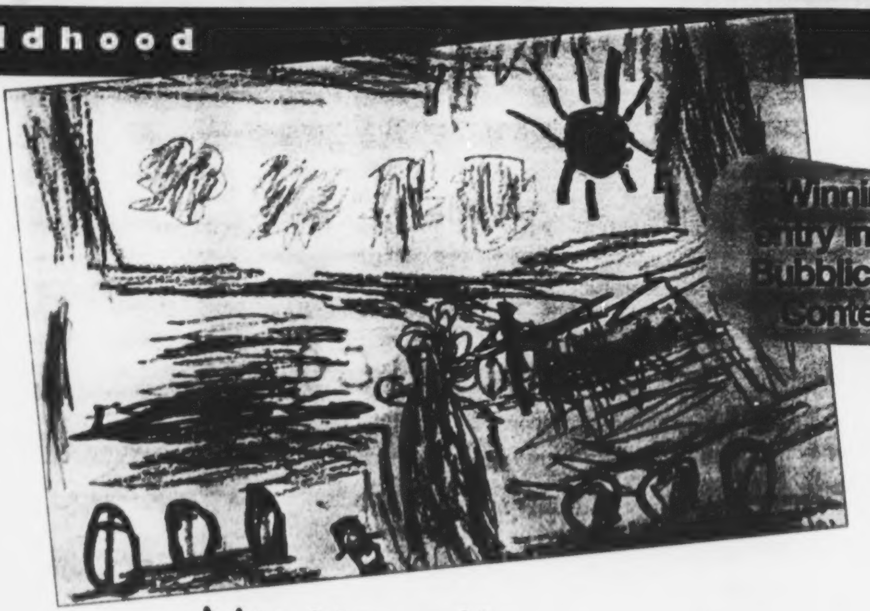
Circle #34

In the December 1997 issue of Exceptional Parent magazine, Bubblicious® chewing gum and the organization Wing & Wheels Inc., a greeting card company which features individuals with special needs, announced a drawing contest for children with special needs. Contestants had to be between the ages of 6 and 17, and the drawing had to be a picture of a location anywhere in the United States. If selected as the Grand Prize Winner, the artist and his or her immediate family would win a vacation to that spot.

One hopeful contestant was budding artist, Bianca Andrews of Newark, New Jersey. Bianca, who has cerebral palsy, submitted a drawing of herself in sunny Hawaii. Over the summer, then 8-year old Bianca received an exciting phone call. Her drawing of Hawaii had been selected as the Grand Prize Winner. Bianca, mom Vivian, Aunt Melba, and cousin Amanda would be heading out to tropical Hawaii for a week of fun in the sun. According to Bianca, the things she was looking forward to the most were,"Watching the hula girls dance, eating coconuts, and swimming in the beautiful Pacific ocean" Bianca also confessed that the children at her school have treated her like a movie star, and some students even asked if they could accompany her!

Bianca and her family made that trip this past year. Recently, EP caught up with Bianca and her mother to find out how the trip went. According to Bianca's mom, they had a wonderful time and spent lots of time relaxing poolside. The group also had the opportunity to hula dance on stage. This truly was a dream vacation. At right is a letter that Bianca wrote to EP describing her time in Hawaii. **EP**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Contes

My Hawaiian vacation

by Bianca Andrews

I have always wanted to go to Hawaii, mostly because I wanted to see the hula dancers. I wanted to get up on stage with them and dance. When we went to the Luau. I got up on stage with my mom, cousin Amanda, and Aunt Melba to learn how to hula, which is not easy for me. This was the best part of my vacation. I also liked the beautiful beach and they had a great big swimming pool at the hotel where we stayed. We spent most of our day at the pool. I would say this vacation was a dream come true.

Bianca

Far left, Bianca, her mother, aunt, and cousin enjoy the sights and sounds of a Hawaiian Luau. Right, Bianca's smile says it all. This was a dream vacation.

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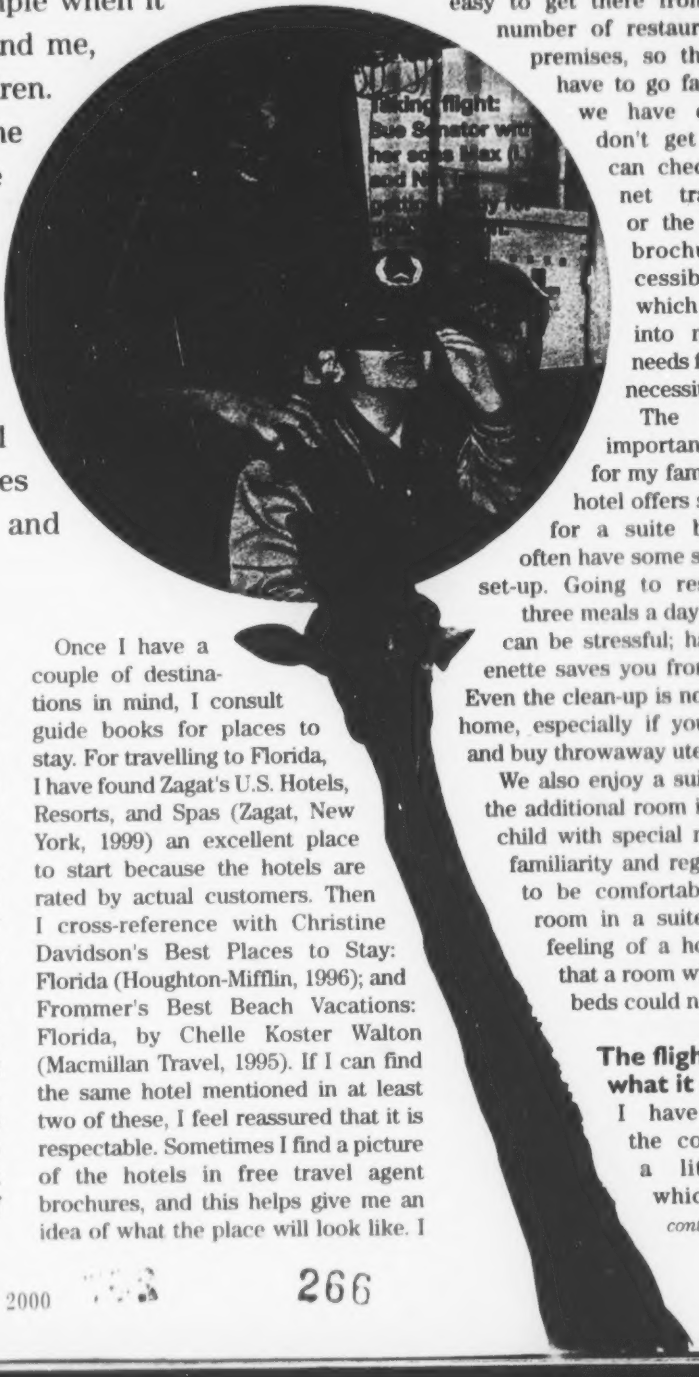
A05 Circle #43

The Secret To Happy Vacations

By Susan Senator

Vacations were fairly simple when it was just my husband and me, but now we have three children. The oldest has autism, and the youngest is a toddler. Yet we manage to take one warm weather vacation a year, without a great deal of stress or unreasonable expense. There is an art to travelling with a special needs child, which lies partially in the details, and partially in attitude.



Destination: organizing our desires

When planning where we are going, I decide what is important for the grownups, and what is necessary for the children. Warm weather is first and foremost to my husband and me, so our destination is based on a hot climate. The kids will do fine there, too. It cannot be just any exotic hotspot, however; a six-hour flight to the Caribbean is out of the question for us. A flight that involves changing planes more than once is as well. We have always settled on Florida, but we go to different parts each year. I get an idea of travel times by looking through travel agent brochures, then going to a Web site like http://www.expedia.com or http://www.travelocity.com. That way I can get a general idea of the time and cost of flights before I commit to anything.

Once I have a couple of destinations in mind, I consult guide books for places to stay. For travelling to Florida, I have found Zagat's U.S. Hotels, Resorts, and Spas (Zagat, New York, 1999) an excellent place to start because the hotels are rated by actual customers. Then I cross-reference with Christine Davidson's Best Places to Stay: Florida (Houghton-Mifflin, 1996); and Frommer's Best Beach Vacations: Florida, by Chelle Koster Walton (Macmillan Travel, 1995). If I can find the same hotel mentioned in at least two of these, I feel reassured that it is respectable. Sometimes I find a picture of the hotels in free travel agent brochures, and this helps give me an idea of what the place will look like. I can use this picture later on when explaining to my child with special needs where we are going.

Accommodations

I choose the hotel based on a few things: whether the place has an interesting pool, so that the kids will have some exploring to do while swimming; proximity to the ocean, so that it is easy to get there from the room; number of restaurants on the premises, so that we don't have to go far to eat, but we have choices and don't get bored. You can check the Internet travel agents or the travel agent brochures for accessibility, too, which will figure into many special needs families' list of necessities.

The final, most important condition for my family is that the hotel offers suites. We opt for a suite because they often have some sort of kitchen set-up. Going to restaurants for three meals a day with children can be stressful; having a kitchenette saves you from that hassle. Even the clean-up is not as bad as at home, especially if you do take-out and buy throwaway utensils.

We also enjoy a suite because of the additional room it gives us. My child with special needs requires familiarity and regimen in order to be comfortable. The extra room in a suite conveys the feeling of a home in a way that a room with two double beds could not.

The flight: doing what it takes

I have found that the construction of a little booklet which I call "Crisis

continued on page 48

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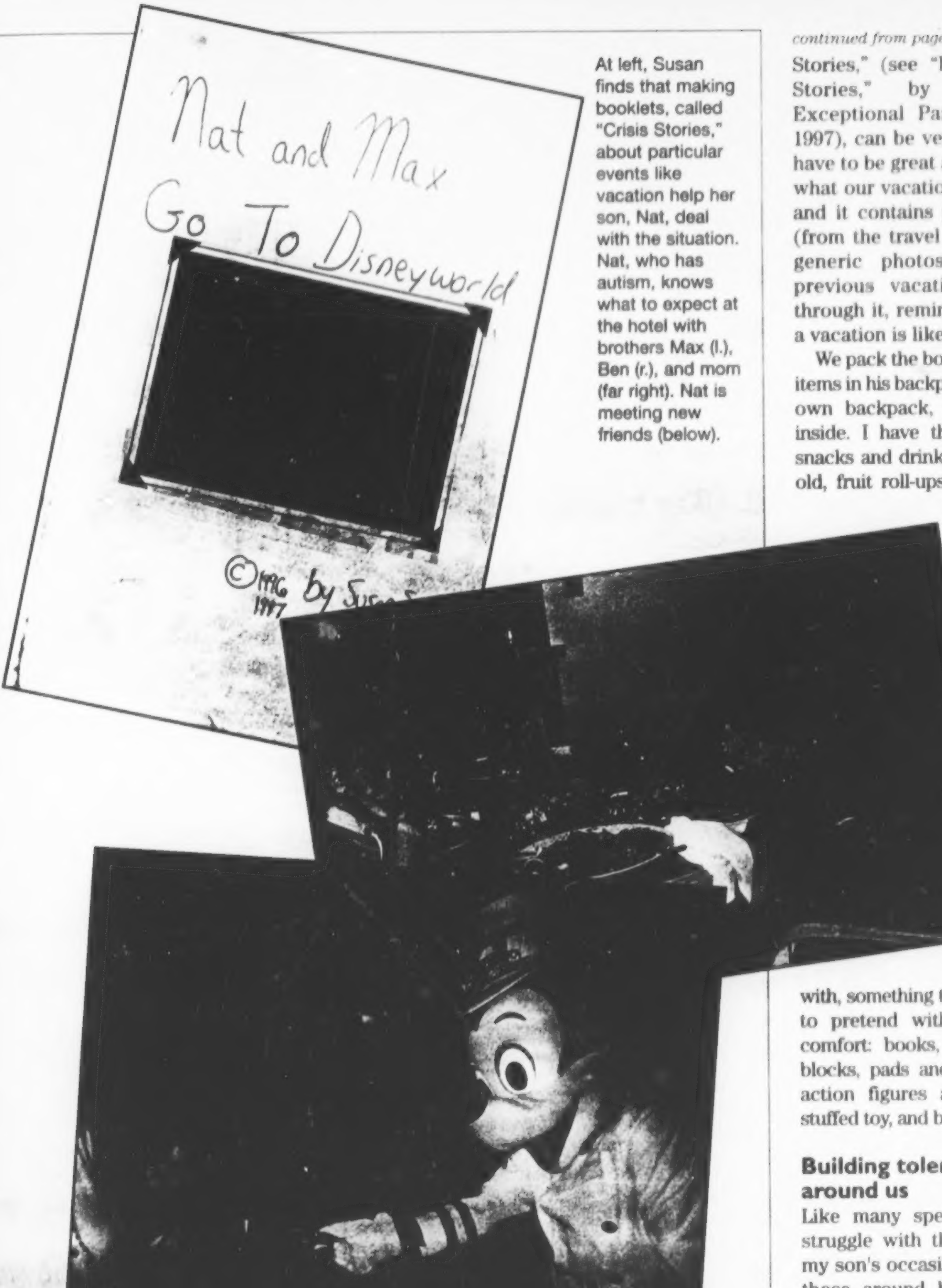


At left, Susan finds that making booklets, called "Crisis Stories," about particular events like vacation help her son, Nat, deal with the situation. Nat, who has autism, knows what to expect at the hotel with brothers Max (l.), Ben (r.), and mom (far right). Nat is meeting new friends (below).

continued from page 46

Stories," (see "How to Write Crisis Stories," by Susan Senator, Exceptional Parent Magazine, July 1997), can be very useful. It does not have to be great art; it merely explains what our vacation will be, and where, and it contains pictures of the hotel (from the travel agent brochure) and generic photos of my child on previous vacations. My son leafs through it, reminding himself of what a vacation is like, and what to expect.

We pack the booklet and other special items in his backpack. Each child has his own backpack, with his own things inside. I have them pack appropriate snacks and drinks—gum for my 7-year-old, fruit roll-ups for my son who has autism, who does not understand that you should not swallow gum, and a bottle for my toddler. As much as possible, I have them decide what they need to bring with them. This is the bag that holds all the toys for the entire trip, so it must be packed wisely. My general advice to them is to bring something to read, something to build with, something to draw with, something to pretend with, and something for comfort: books, a baggie of legos or blocks, pads and crayons, a couple of action figures and vehicles, a small stuffed toy, and blankies.

Building tolerance in those around us

Like many special needs parents, I struggle with the issue of explaining my son's occasionally odd behavior to those around him. When we travel, there are ways of telling without actually "telling." For instance, when we are boarding the plane, I speak to my son in a slightly louder voice than usual, complimenting him warmly when he follows my instructions. This way, people watching get the idea that something is a little different with this child. That's all they need to know. I make eye contact with anyone who stares, and I smile at them and at my son. Smiling goes a long way. I act happier than I may be feeling, and this helps relax my child(ren) and conveys ease and competence to the adults around me. They are then more likely to shrug off the occasional bump or kick, especially when I apologize and remind my child to apologize. This lets people know that we are working on these things; that this is not about "poor parenting" or "bad behavior." There will always be some people who will not understand, but we will not let this disrupt our vacation.

THE MORE FAMILIAR STRUCTURE MY CHILD WITH SPECIAL NEEDS HAS, THE LESS ANXIOUS HE FEELS, AND LESS PRONE HE IS TO DISRUPTIVE BEHAVIOR.

Special treatment

Many amusement or theme parks can be wonderful for kids with special needs. They are great because they strive to accommodate, and we have benefited from a special pass picked up at the ticket booth, which we got with a note from our doctor. I advise that you call ahead first and explain your situation; it is not a given that you will get the pass. Once you have the pass, your child will not have to endure most long lines that are hard for any child to take, but even harder for children with disabilities like autism and attention deficit disorder. Many of the attractions have separate entrances for people with disabilities, or a staff member simply escorts your child (and his family) to the front of the line! Be forewarned that some guests do not appreciate the situation of the special needs family. Our child has a disability you can't necessarily see, and this caused some visitors to question our actions. Try not to feel guilty; you have paid your dues already! For once, something has come easy for your child; take it and enjoy it!

Making routines

Our vacation success as a special needs family also comes down to getting into a routine each day. Meals are a good place to start. Take the same table in the corner each day, and eat lavishly for an hour for breakfast. Lunch is often the hardest to routinize, since we are likely to be out and about. We try to do the same thing each day for lunch, and save the variety for dinner. The front desk often has someone who is happy to direct you to local kid-friendly restaurants, if the hotel restaurant is too grownup for your family.

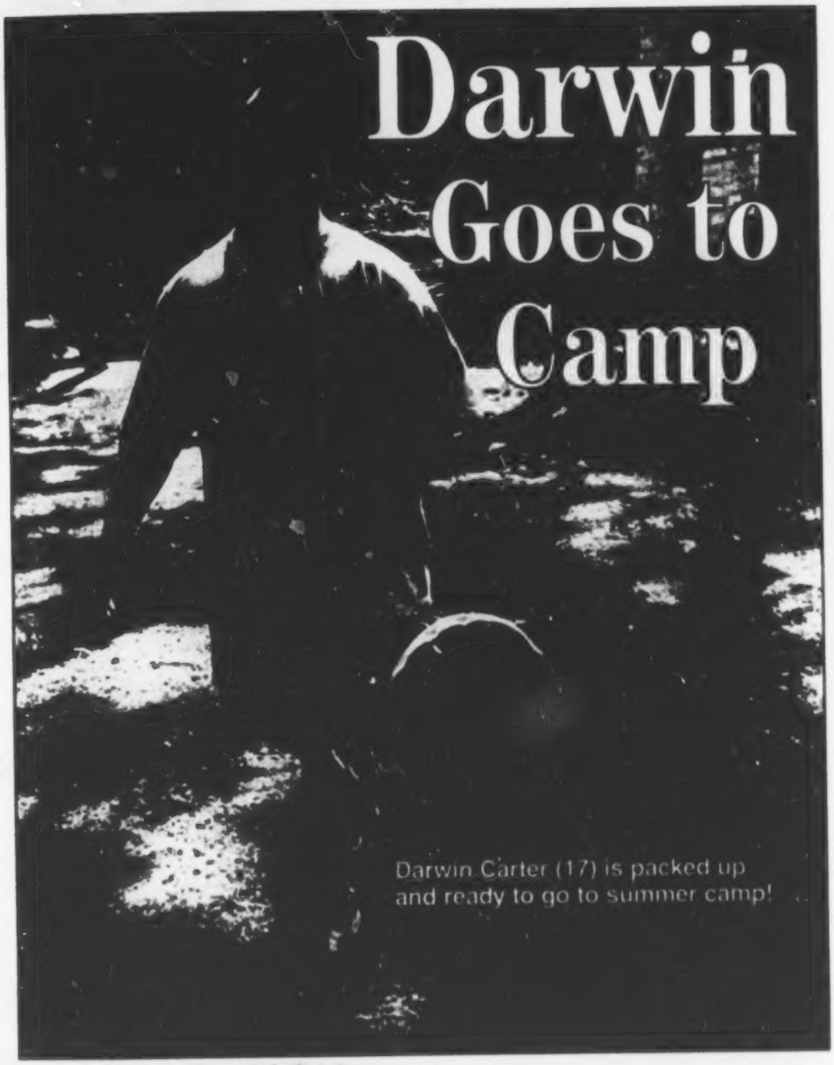
There are also the activity routines. Each morning, we try to outline our plan for the day, using visuals if we've got them. We explain when and where we will eat, where we will go first (pointing to the pool, the ocean, or using a hotel brochure picture), when we will come back to the room. The more familiar structure my child with special needs has, the less anxious he feels, and less prone he is to disruptive behavior. On the day of departure, we explain about the long plane ride, the waiting, the drive home, and finally, arriving at our house.

A vacation is yours to invent

Routines and schedule recitations are my son's anchors. As he repeats the items in order, and asks us to fill in the blanks, he begins to be soothed by their form and their content. Once he understands what will happen, he begins to relax, and then so do we. It's not always easy or smooth. By being aware of our priorities and adhering to them, we manage to take vacations like most families, without a lot of extra expense and worry. And by being cognizant of the unique strengths and weaknesses of our family, we find our own particular way of having fun and staying happy. I believe that any special needs family can come up with their own list of priorities and necessities for having fun, and succeed in taking the vacation of their dreams – or close to it. Special needs parents know more than anyone else that nothing is perfect, but you sure can try! **EP**

Susan Senator and her family live in Massachusetts, where Susan is the Co-chair of the Brookline Special Education Parents Advisory Committee.

Darwin Goes to Camp



Darwin Carter (17) is packed up and ready to go to summer camp!

CONFESSIONS OF AN ANXIOUS MOTHER

by Susanne Carter

It is 3 a.m. on a Sunday morning in late June, and I am wide awake with maternal anxiety. Although everyone else in the family is sleeping peacefully, I am trying to convince myself that I can overcome my apprehension and take my 17-year-old son (who has a unique combination of Down syndrome, autism, and severe mental retardation) to camp. If it is possible to both look forward to and dread something at the same time, this describes exactly how I feel right now.

Parting with Darwin

This is the day I have anticipated for months with excitement, like a child counting down the days to Christmas. This is my opportunity for five days of blissful freedom from Darwin's constant care. Just think...

- No diaper changes for five days;
- No middle-of-the-night interruptions for five days;
- No listening to the same rock music over and over and over for five days;
- No exciting "adventures" for five days, such as taking apart the toilet in search of the toothbrush that Darwin has flushed or trying to inconspicuously retrieve the underwear that he has abandoned and tossed over the fence into the neighbor's yard;
- Essentially no "Darwin duty" for FIVE WHOLE DAYS!

I am not sure I can part with him. I am already missing my son before we leave home. This will be Darwin's third summer at camp. You would think I would have adjusted to the separation by now. Although it has become easier each year, I always find it difficult to part with my son.

If only Darwin could somehow communicate to us that he wants to go to camp. If only he could anticipate this day with excitement, as I do.

Even a child with limited communication ability such as Darwin can express his preferences. Just try playing a Dire Straits CD when he is in the mood to rock to the Moody Blues and he will "tell" you something about preferences.

We try to build choice into Darwin's life at every opportunity, recognizing that it is self-empowering for him to be able to make his own choices. However, "camp" is not a tangible part of our family's regular routine, and Darwin does not have the ability to

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relate with photographs or other forms of symbolism. For Darwin, going to camp is not a choice he can make for himself. It is one we are making for him— and for ourselves.

Now that the long-awaited day is here, the "what if" monster will not let me sleep:

- What if Darwin refuses to sleep and giggles all night, keeping everyone in his cabin awake all night?
- What if he escapes and no one can find him in the surrounding woods?
- What if Darwin's "evil twin brother" (as we affectionately refer to Darwin when he is in one of his mischievous phases) suddenly surfaces and becomes aggressive?
- What if he suddenly decides to take a dip in the pool in his birthday suit?

I know my son. I know any of these scenarios could easily happen.

Now that Darwin and I have survived three summers of separation, when he goes to camp and I reflect back upon our respective experiences, I realize the he and I both have come a long way in our adjustment to this new adventure.

The first year

The first year we sent Darwin to camp was understandably the hardest. We made a visit to the camp ahead of time with Darwin and liked what we saw. He would certainly enjoy the swimming pool, merry-go-round, basketball courts, hiking trails, nightly dances, rocking chairs outside of every cabin, and Snickers™ on demand at the canteen. We also had a lengthy discussion with the camp director, who assured us that the staff was experienced dealing with active, exploratory "Darwin-type" campers who require intensive on-on-one supervision. Despite these reassurances, I wasn't sure I could leave him, even if the camp met Darwin's utopian ideal of the perfect summer camp—pizza every meal and continuous rock music—or mine, Darwin mellow and happy every moment, and by the end of the week, talking in complete sentences and fully toilet-trained.

In his 17 years, Darwin had never spent a night away from home without us. We were about to leave him in a strange place with people who, although obviously caring and experienced in working with individuals with varying disabilities, hardly knew Darwin or his idiosyncrasies.

Parents of "normal" infants and toddlers experience a similar apprehension when they leave their children in new places or with new caregivers. Those of us with children who have severe disabilities like Darwin may never really move beyond this stage; our children grow up but essentially they remain infants in their inability to express their wants and needs., their helplessness, their

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Survival Tips for Anxious Mothers Sending Their Children to Camp:

1. Choose the camp best suited to the needs of your child. Use the Internet, other parents, and local social service centers as resources. Other resources are the American Camping Association, 5000 State Rd. 67 N., Martinsville, IN 46151; phone: (800) 428-2267; fax: (317) 342-2065; and the National Easter Seal Society, 230 W. Monroe, Chicago, IL 60606; phone: (800) 6827; TTY: (312) 726-4258.
2. Visit the camp of your choice, exercise your right to ask any and all questions, and make sure you feel good about the environment, the program, and staff before deciding to send your child.
3. If you need to, call the camp each day. You can make arrangements for the camp to call you if there are problems.
4. Take your child's "resume" along with the highlights of his/her likes and dislikes, behaviors, interests, idiosyncrasies, needs, etc. (Counselors tell us they really appreciate this)!
5. Remind yourself that the first year is the hardest.
6. Use your imagination and visualization as an aid: whenever you wonder or begin to worry about your child, visualize him or her having the time of his/her life at camp. Do not visualize negative images.
7. Look at this time away from your child as an opportunity to redefine yourself apart from your child.
8. Make a list of things to do (work and/or play) while your child is away that his/her care prevents you from otherwise doing.
9. Take at least one nap a day.
10. Remind yourself that you earned this freedom, again and again if necessary.
11. Savor the anticipation of reunion with your child.

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vulnerability.

Armed with a "resume" detailing everything you would ever want to know about Darwin if you were his camp counselor, we resolved to give camp a try that first year. We consoled ourselves with the fact that the camp was located only 88 minutes and 45 seconds away from home, just in case it did not work out. And we had the assurance of the camp director that she would not hesitate to call if there was trouble.

We drove away with image of Darwin bouncing a ball, seemingly oblivious to our leaving (and grieving). I felt a huge lump begin to swell in the back of my throat.

The phone call came minutes after we arrived home to a much-too-quiet house. Darwin's "evil twin brother" had already made an appearance, accompanied by some unexpected hitting and pinching. With some careful behavior management coaching over the telephone, my husband was able to offer suggestions that worked until Darwin settled into the new camp routine.

Darwin's experience

Although the "evil twin brother" made an early appearance at camp, Darwin soon adjusted and seemed to enjoy his stay, according to his counselors. It was not surprising to hear that he did not sleep well, but he amazed his cabin counselors with his ability to swim and liked the dance parties at night. After five days of Darwin duty, they did not look too worn out when we arrived, and it was obvious they had bonded with him.

Perhaps Darwin thought we had abandoned him. For when we arrived to take him home and showered him with tears and hugs, he tolerated the enthusiastic display of affection for a few seconds and then stepped back to examine us thoughtfully. He was NOT happy that we had almost abandoned him.

Transitions like these are especially tough for our kids. Darwin was not the only camper "unloading" on his parents. Once Darwin finished his brief outburst, however, he calmly took us by the hand and headed for the car.

Mom's experience

As we left Darwin at camp the first summer and headed home, I was enveloped by an overwhelming sense of loss. My husband and I both arranged to take the week off from our respective jobs and had a lengthy list of

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house projects to tackle, all of them virtually impossible to do with Darwin under foot. I knew I needed to keep busy. I carefully hid all his toys in the closet and avoided anything that remind me of him.

I cried a lot, especially the first day. As much as I knew I needed this freedom, I was not sure I could survive the five days ahead. My youngest son, then 11, wanted to know if I would cry as much if he decided to go to camp. Although sibling rivalry is not a big issue in our house, he needed the reassurance that he would be equally missed.

As the week progressed, I cried less and began to adjust to my newfound freedom. It began to dawn on me that for the first time in 15 years, I could spend each precious day as I wanted!

Reflections

During the past three years, I have come to realize that Darwin needs these five days away from us as much as we need this time of freedom. Although we hire respite care providers (when we can find brave ones willing to work with an incontinent 17-year-old with challenging behaviors). Darwin has no real friends, other than his loving family. As a young adult, he needs to break away from us and socialize more with his peers. He needs this opportunity for independence and growth (as we do).

As Darwin has gradually become better adjusted to the camp routine each summer, so have I. It is my opportunity to redefine my roles of wife and mother and spend more time with the other two men, my husband and other son, in my life. It is my opportunity to let go of my son—just a little. **EP**

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A JOURNEY OUT OF DARKNESS

A mother's recollections of caring for her daughter with multiple disabilities

by Mary Ann Veade

Clockwise from left: Elizabeth proudly shows off her completed homework; Elizabeth in her incubator as a newborn; and riding her bike near her home.

The wheels of the school bus can be heard as it makes its way down our street. "Hurry," I sign to my curly blonde-haired, blue-eyed little girl as she boards the bright yellow school bus. A kiss on the cheek and the sign of "I love you" start another day. As I turn to walk back to the house, I wipe away a tear that has managed to cloud my vision. It is partially a tear of sadness for my selfishness of wanting to keep her all to myself, but mostly of happiness in seeing this child, our child, walk away so proudly and independently.

For most first-grade children, boarding a school bus seems quite an easy task. However, for Elizabeth, who struggled at birth to live and who, according to doctors, would never have use of her arms or legs, this is quite an accomplishment. And yes, as you might have guessed by now, she is also deaf. I close the door softly behind me. I take out my journal that I have kept since her birth and take a step back in time.

The day October 31, 1991, will always remain a very special one in our lives, for it was on this day that our little Elizabeth was born. Born just two weeks early and weighing a mere four and one half pounds, our daughter came into this world fighting for her life. My husband and I were told that our baby girl would probably have brain damage and would most likely have less than a year to live. The manner in which we were given the diagnosis was so cold and unfeeling. The doctors seemed not to care as they rattled off the grim prognosis for our daughter. Other potential challenges such as deafness were also discussed. Her deformed feet led them to believe that she would also be crippled.

I remember trying to place myself somewhere else, for if I could be somewhere else this horrible experience would not be happening. I did not want to hear what was being told to us. I did not know which way to turn, and the lump in my throat would not go away. The tightness in my chest persisted and my feelings of desperation and helplessness increased. Questions bombarded my mind every day. Why did I feel all alone? What could I do to help? Why did this happen to us? What did I do wrong? Was I being punished? Did I do something during my pregnancy to hurt this little helpless infant?

We were able to take Elizabeth home when she was twelve days old. While playing with her one day, I clapped two shoes together in front of her face only to receive a blank stare from the infant looking back at me. Deep down inside I knew this was not a normal response. On January 23, 1992, our lives were changed forever, for it was on this day one of my worst fears was confirmed.

I held my tiny three-month-old daughter Elizabeth in my arms as the audiologist placed the electrodes on her scalp. Each time a sound was emitted from the machine, I watched anxiously to see if Elizabeth would respond. Each time a quick glance at the audiologist's face revealed the horrible truth I did not

Above: the Veade family—(from left to right) daughter [illegible] 12, son, Thomas, 17, Mary Ann (mom), Elizabeth, 8, Webster (dad), and [illegible] Christine, 15. Left: Elizabeth's graduation day from Bright School [illegible] 6.

want to face. My fears became a reality. Our three-month-old baby girl was living in a world of silence. I felt numb as my husband and I sat there trying to absorb the news just revealed to us. I felt as if a ton of bricks had been dropped on my chest, and a tremendous feeling of helplessness enveloped me. We watched two video tapes about different modes of communication to use with deaf children. As I sat there watching, nothing seemed to sink in. The word "deaf" got stuck in my throat every time I tried to utter it. The tapes ended and we were given advice about getting Elizabeth started in an early-intervention program.

The drive home was a solemn one. Finally we arrived. I remember feeling like not doing much of anything. It was as if life had stopped. I did not care what I looked like and did not care to go anywhere or do anything. The dreadful hours lapsed into days, the days into weeks. I often thought about the woman who showed us the video tapes and encouraged my husband and I to call the principal at Bright School in New Orleans to inquire about an early-intervention program for Elizabeth. Several times I wanted to pick up the phone, but my hand would not, could not, reach for it. I was numb, frozen in a state of helpless despair, and I could not break free.

Finally one day the phone rang. It was the same lady from the hearing center asking if I had called the principal. When I told her I had not, she offered to call on my behalf. I agreed, knowing that I had to move on if I were to be of any help to Elizabeth and our other three children. Two days later the principal called, and we were now on the road to finding help for Elizabeth.

A whole new world

Elizabeth was enrolled into Bright School in New Orleans at the age of three and a half months. It was here that she received the foundations upon which she would build her language. While going to school, there were many days that were missed due to operations on her hands and feet. The days were often intertwined with visits to doctors, not to mention the numerous therapy sessions that ensued. Fortunately, each therapy session as well as each operation proved to be an improvement to Elizabeth's health and well-being.

The day is Tuesday, April 22, 1996. The place is the hearing center. The room—the same room where it all began. This time my husband and I are here to talk about cochlear implants. Again, questions bombarded my mind. Is this the right decision? Will a cochlear implant help our daughter's hearing? Will she be angry with us? Are there risks involved? What if it does not work?

This was one of our most difficult decisions since Elizabeth's birth. Other decisions we had made, such as agreeing to an operation that would enable our child to walk, were much easier. We knew that this decision would mean a lot of work on our part and on hers. We also knew that it would mean years of speech therapy and tons of patience. On June 16, 1996, after much prayer and deliberation, Elizabeth received her cochlear implant.

With eager anticipation, we waited. Was the surgery a succes[illegible] she actually be able to hear m[illegible] and other sounds?

One day, my answer [illegible] was working with her at the kitchen table. The sound I always abhorred, the dryer buzzer, caused Elizabeth to jump up and hand me the phone. With anxiety in my voice, I said and signed to her, "Did you hear that?" When she signed "yes" back to me, I knew that a whole new world was about to unfold for her. Years later, I would be proven right when she spoke a full sentence to me in the hospital. She was recovering from one of her operations and called out to me in the middle of the night, "Mother, mother, want more ice." This is the stuff that faith and dreams are made of.

Faith, family, and a simple phone call

Certainly a lot has taken place in Elizabeth's life so far. My feeling of desperation is slowly dwindling away. I know it will never be gone forever, for a little part of me will always remember the tightness in my chest and inability to breathe upon receiving all of the information the first few days of Elizabeth's life. The grim look on everyone's faces will be burned in my mind forever, as will the feeling of helplessness when I heard that

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- I first wondered if Elizabeth would live—she did.
- I wondered if she would walk—she does.
- I wondered if she would learn and understand—she can.
- I wondered if she would ever hear and turn to her name—she is now able to.
- I wondered if I would ever laugh or feel happiness again—I do.

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Elizabeth was deaf. She might not ever enjoy one of my bedtime songs or perhaps never hear the sincerity of my voice when I tell her "I love you." No, these things are certainly not easy to accept or forget, but at the same time I can now look with hope to the future.

When I reflect on my experiences of taking care of Elizabeth, I am drawn to thoughts on how I made it through some very difficult years. First and foremost, there was my family, especially my husband, Webster. I remember how he—and our parents—stuck by my side constantly in the hospital, as I was too devastated by my daughter's prognosis to think straight. My faith in God and the sisters and pastor who prayed with and for us helped a great deal as well. Then there were my friends, the family counselor at Bright School, and the person who encouraged me to write a journal. Thank goodness I had such a strong support system. Thank goodness I had the encouragement to work past the guilt and anger and concentrate on helping my daughter.

Finally, I must mention the importance of that very first call from the concerned woman at the hearing center. That simple phone call marked the beginning of the end of my acute state of denial and helplessness. She urged me to make inquiries, ask questions, and seek out advice. She—and others—reached out to me, letting me know that we were not alone, and that made all the difference in the world.

It is September 16, 1999. I hear a familiar sound of wheels turning. I see the color of bright yellow peeking between the trees. The screech of the brakes tells me my special someone has arrived.

Proudly, backpack stretched over her shoulders, she exits the bus. A little tired from the day's activities, she manages one of her irresistible smiles. We walk into the house. After a snack, she is ready as always to begin her homework.

She writes her name across the top of the page. "Elizabeth". I contemplate for a moment and remember the meaning of the word "Elizabeth": Gift from God. She truly is our gift from God.

I close my journal. Tomorrow begins another day. **EP**

Mary Ann Veade is a parent and also the Family Voices State Coordinator for New Orleans, Louisiana.

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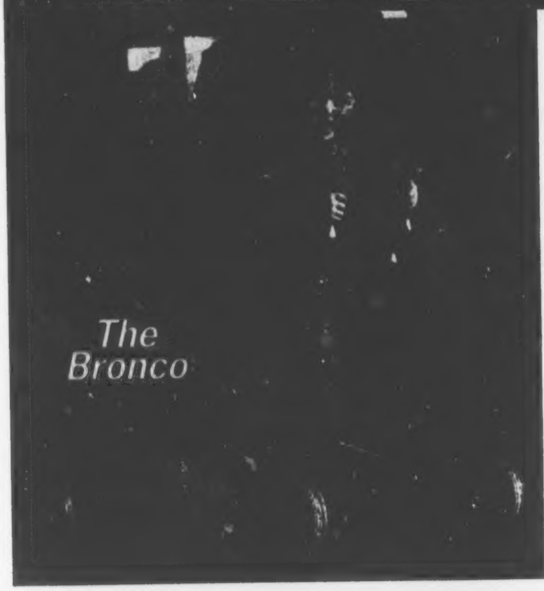

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EXTRAORDINARY PARENTING

THE POWER OF ATTITUDE in Reaching Children with Special Needs

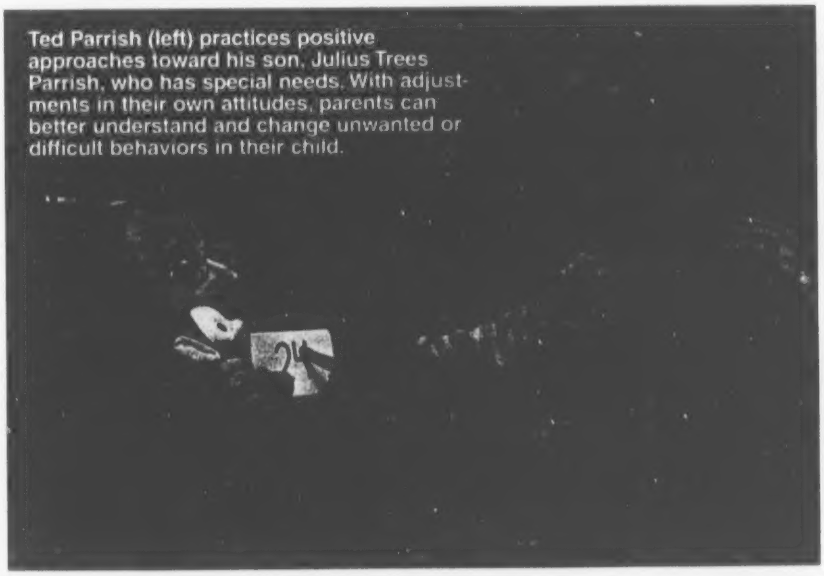
by Steven R. Wertz, MA, with Kaitryn Wertz

Attitudes, thoughts, and feelings are important when we parent a child, and have a greater impact on our effectiveness than techniques or strategies. Parents who examine and change their own thoughts and feelings become more effective in virtually every circumstance. By understanding the role of our attitudes, we become less likely to reinforce and teach unwanted behaviors in our children. We also become more capable of inspiring our children to develop self-confidence, the desire to learn, and the strength to overcome difficulties.

This principle is especially important in extreme situations. I have worked with parents whose children break glass, throw food, smear feces, bite, kick and spit. Why do children do these things?

I have found, from my experience working with parents and teachers, that the most powerful and effective approach with children who have special needs is a marriage of mind and heart, science and attitude. We can meet the challenge by strengthening both. Consider Kevin, 12, who has autism, and his father, Joe. Joe was very concerned about Kevin's aggressive behavior. Kevin often hit, kicked, scratched, or bit people. The only way Joe could stop him was to restrain him, or, if all else failed, hit him. But Kevin's aggression was escalating, and Joe was at his wit's end.

When Joe and I later discussed his reactions, Joe revealed his fear that Kevin's behavior was a reflection of poor parenting. He felt inadequate to handle Kevin. As he explored his feelings, he began to change his outlook. He decided that Kevin's behavior was not a reflection of bad parenting, but an indication that "normal" parenting was occurring where extraordinary parenting was necessary. Joe realized that he could use Kevin's outbursts as opportunities to find the extraordinary within himself. Instead of focusing on how to stop Kevin, Joe now wanted to help Kevin learn to interact gently.



Ted Parrish (left) practices positive approaches toward his son, Julius Trees Parrish, who has special needs. With adjustments in their own attitudes, parents can better understand and change unwanted or difficult behaviors in their child.

The next session was very different. When Kevin kicked Joe, Joe said softly, "Kevin, no matter what you do, I'm never going to hit you again." Kevin grew more agitated and tried to kick his dad again. Joe moved out of the way and repeated his statement. Kevin started to cry. He said, "I'm supposed to kick you and you're supposed to hit me. That's how we do it."

For Kevin, the violent interaction was a ritual. It was consistent and predictable, and it provided him with attention. Joe had unintentionally reinforced Kevin's behavior with his angry reactions.

Attitudinal training helps parents become comfortable with the challenging behaviors of their children. When parents change their feelings about such behaviors, both the frequency and intensity of the incidents diminishes.

As was the case with Joe and Kevin, when we are uncomfortable, we are likely to react in ways that reinforce

Difficult behavior in their child is a challenge for parents. By changing their own attitudes and approaches, parents can help improve the situation.

Child's Behavior	Parent's Attitude	Parent's Approach
Pinching, hitting, hair pulling, etc.	No discomfort with the behavior. Accept that your child is doing what he or she can to interact.	1)Take care of yourself—get out of the line of fire. 2) Do not react to or reinforce the behavior. 3) React more dramatically to gentleness and affection.
Whining, crying and apparent distress.	Trust in your child's ability to handle what is happening. Do not pity. Feel strong and peaceful and your child will pick up on that.	Be present and helpful without rewarding their distress, as this "teaches" unhappiness. Reward emotional strength and clarity.
Yelling "NO!" and refusing to do something (like bathe).	No reaction of frustration. Understanding your child's desire for control.	Show your child that yelling does not push your buttons or get you to back off from your request. Persist with the bath, and offer control of what toy is brought to the bath, the water temperature, etc.
Not eating certain healthy food (like broccoli).	Create in yourself a love of broccoli that surpasses your love of ice cream (at least temporarily).	Model—eat the food and express your delight in it. Get other family members to participate. React with delight when your child takes a taste.
Not participating in curriculum, therapies, etc.	Foster within yourself an uncommon delight in the material or in the therapy.	Demonstrate your love of the material. Show your child how it will benefit them. Show how doing it is fun.
Fear of failure, not wanting to make mistakes.	Have no fear of failure— your own or your child's. Enjoy mistakes. They are the stuff that learning is made of.	Cheer all answers first. If you ask what is 2+2 and your child says 5, celebrate. Then "check" and discover that it is four. Accept your own mistakes in your child's presence.
Emotional upset around certain specific events (like being called names by other children).	These events are not to be avoided. They are cherished opportunities to parent. Help your child learn to digest them.	Recreate the troubling event, giving strategies for coping, and a framework for understanding.

the very behavior we do not want. When we become comfortable with the same behavior, we are able to shape our responses in order to elicit the behavior we want.

We can also use attitude as a powerful educational tool. When encouraging the development of new skills, our primary job is not to focus on a particular subject, but to teach a love of that subject or skill. For example, 3-year-old Sarah babbled, but she never imitated sounds or spoke words. Sarah had one great love in her life: Cheerios. In this particular instance, she sat on a stool with a bowl of Cheerios on a nearby shelf. She was babbling and disen-

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gaged. In the middle of random sounds, she made a noise vaguely like "O". Her teacher said, "O's?" He jumped theatrically, ran, grabbed Cheerio's, and thrust them into Sarah's hand—repeatedly saying, "O's!"

Sarah looked at the cereal and softly said, "O." She laughed, beginning a game in which she periodically called out "O's" and the teacher raced for the cereal. Her typical blank expression was replaced with a huge grin. Sarah was not just making a sound. She was delighting in the power of sound.

Behaviorism focuses on behavior, without emphasizing the importance of the teacher's feelings and attitude. If we focused on behavior rather than attitude, the reinforcer would have been Cheerios. But it wasn't. Often, Sarah did not even eat the Cheerios. The main event and reinforcer for Sarah was the pleasure of using sound to move a person. The key words are pleasure and person. When I train parents, the primary intention is to create pleasure in the activity, and to draw the child into that enjoyment.

This does not mean success is inevitable if our hearts are in the right place. Technical skill and scientific teaching strategies, without focus on attitudes, tend to produce children who are robotic and less emotionally alive. An attitudinal approach, without educational strategy and assessment, results in happier, more interactive children; however, their learning often plateaus without scientific assessment and educational methods.

We strengthen our hearts by recognizing and changing counter-productive attitudes, and by engendering the delight that awakens motivation in children. We strengthen our minds by learning the techniques and principles that research has substantiated. Combining these, we become extraordinary parents and educators who can help our children become more complete, more powerful and more able to achieve their potential. **EP**

Steven R. Wertz, MA, is a consultant to parents and teachers of children with an array of developmental and neurological challenges through Growing Minds programs for children with special needs. With his wife and partner Kaitryn, he directs Special Solutions, Inc., in Jupiter, Fl. For more information the authors can be contacted at: phone: (561) 748-9697; Web site: http://www.specialsolutions.net.

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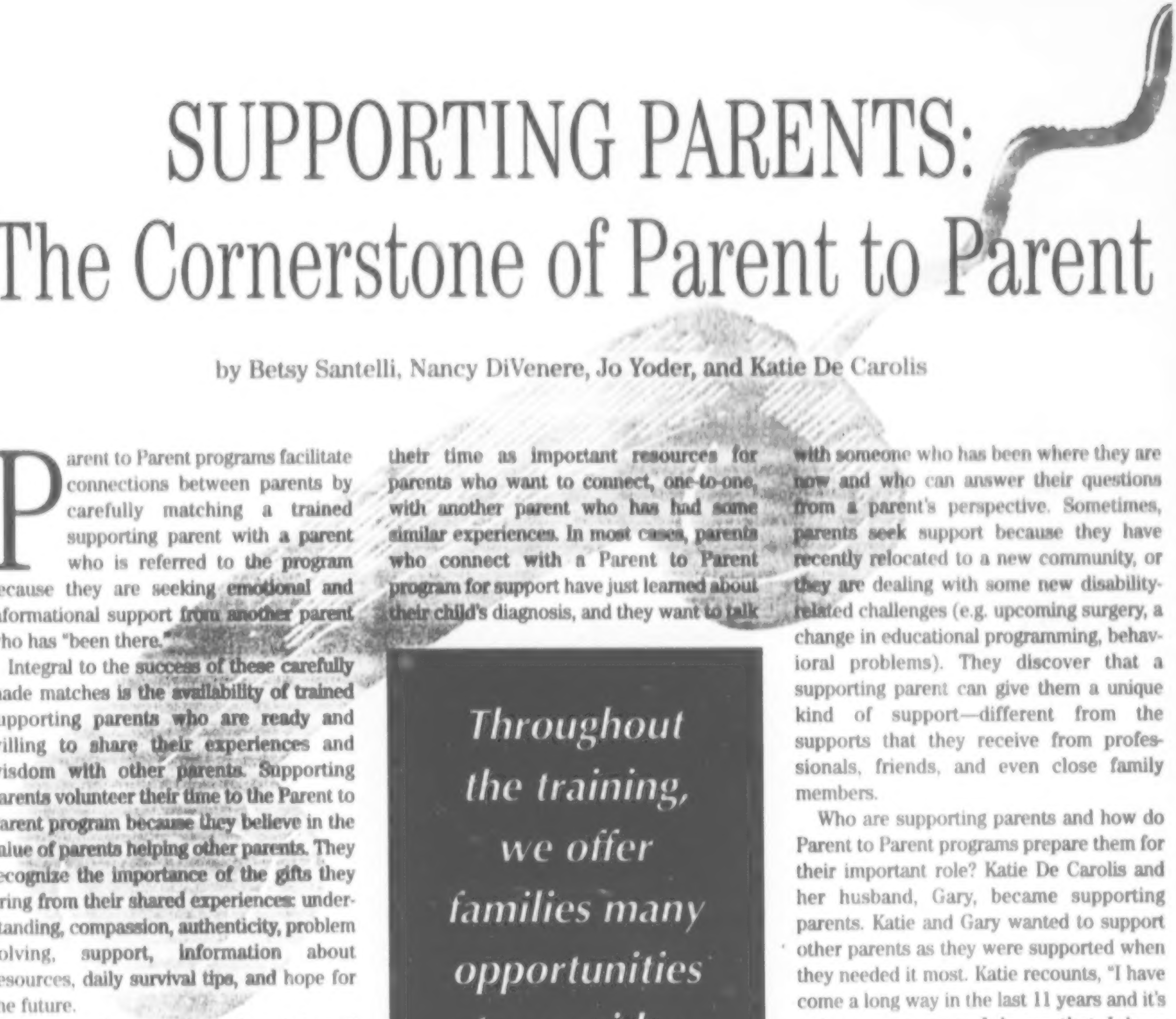
SUPPORTING PARENTS: The Cornerstone of Parent to Parent



by Betsy Santelli, Nancy DiVenere, Jo Yoder, and Katie De Carolis

Parent to Parent programs facilitate connections between parents by carefully matching a trained supporting parent with a parent who is referred to the program because they are seeking emotional and informational support from another parent who has "been there."

Integral to the success of these carefully made matches is the availability of trained supporting parents who are ready and willing to share their experiences and wisdom with other parents. Supporting parents volunteer their time to the Parent to Parent program because they believe in the value of parents helping other parents. They recognize the importance of the gifts they bring from their shared experiences: understanding, compassion, authenticity, problem solving, support, information about resources, daily survival tips, and hope for the future.

These and countless other informal supports provided by parents through the one-to-one parent match are wonderful complements to the services that children with special needs and their families receive from the formal service system. As Katie De Carolis—a parent who connected with Parent to Parent of Vermont first as a referred parent and then as a supporting parent—comments: "Shortly after our daughter Emily was diagnosed with Down syndrome and we were feeling consumed by disability information, my supporting parent helped me to see beyond the disability by bringing me a book about parenting. Just parenting—not parenting your child with a disability—but just parenting. That simple gesture helped me to remember that I was still a mom with a new baby. A horrendous cloud started to lift at that very moment."

There are over 40,000 trained supporting parents nationwide who are volunteering their time as important resources for parents who want to connect, one-to-one, with another parent who has had some similar experiences. In most cases, parents who connect with a Parent to Parent program for support have just learned about their child's diagnosis, and they want to talk with someone who has been where they are now and who can answer their questions from a parent's perspective. Sometimes, parents seek support because they have recently relocated to a new community, or they are dealing with some new disability-related challenges (e.g. upcoming surgery, a change in educational programming, behavioral problems). They discover that a supporting parent can give them a unique kind of support—different from the supports that they receive from professionals, friends, and even close family members.

> *Throughout the training, we offer families many opportunities to consider their own experiences as parents and how they can use these experiences as they support other parents.*

Who are supporting parents and how do Parent to Parent programs prepare them for their important role? Katie De Carolis and her husband, Gary, became supporting parents. Katie and Gary wanted to support other parents as they were supported when they needed it most. Katie recounts, "I have come a long way in the last 11 years and it's not as scary now. I know that I have something to give." Other parents choose to become supporting parents because they did not connect with another parent until months or years after their child was diagnosed, and they want to ensure that other parents do not have to go it alone.

In either case, supporting parents bring years of experience to the match, and the training that they receive before they are matched builds upon their strengths. Nancy DiVenere, director of Parent to Parent of Vermont, explains, "Our supporting parent training helps ensure the success of the one-to-one matches that are the cornerstone of Parent to Parent of Vermont. Throughout the training, we offer families many opportunities to consider their own experiences as parents and how they can use these experiences as they support other parents. The training also gives them some specific

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Circle #52

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tools for careful listening and for communicating with referred parents in ways that make it easy and comfortable for conversations to continue.

The training that Parent to Parent of Vermont provides to supporting parents is typical of that offered by Parent to Parent programs nationally. The results of the national survey of Parent to Parent programs conducted by the Beach Center on Families and Disability indicate that 78 percent of Parent to Parent programs offer at least 4 hours of training (with 44 percent providing more than 10 hours of training) before parents are matched as supporting parents, and in over 80 percent of Parent to Parent programs, the content of the training includes: listening and communication skills, an orientation to Parent to Parent, understanding the emotional adjustment to the diagnosis, and information about disabilities and community resources. Other content areas that are included in the training offered by over half of Parent to Parent programs include: positive philosophy about disability, self-awareness activities, knowing when and how to refer, and advocacy training. Most programs have training manuals available as resources.

In Parent to Parent of Vermont's training course, a facilitator invites parents to share their own family stories and the feelings they experienced when they learned of their child's diagnosis. This intimate sharing serves as a model for their parent matches, and it helps the supporting parents to reconnect with their strong emotional reactions to their child's special needs. A follow-up discussion of the common stages in the adjustment process (e.g. denial, anger, guilt, sorrow) uses the family stories to identify these responses and to emphasize that, while there are common emotional responses, no two parents will experience these feelings in exactly the same way. The facilitator points out that supporting parents are in a unique and credible position to first recognize where in the adjustment process a referred parent may be and then to reassure the referred parent that these feelings are familiar and normal.

Parents write down five things that they value most in life (e.g. family, freedom, self-respect, love) and share these with the large group. Then the parents are told that they must choose two of their values to keep and three to give up. The resulting tension is a great indicator of the importance of personal values, and of how uncomfortable it is to be told to them. The overall discussion that follows provides evidence that everyone has his or her own values, no one can choose values for another, and that values affect the decisions parents will need to make regarding their child with special needs.

> *...everyone has his or her own values, no one can choose values for another, and values affect the decisions parents will need to make regarding their child with special needs.*

All Parent to Parent programs include in their training information about, and time to practice, communication and listening skills. In some programs, facilitators introduce communication and listening skills by asking the parents to recall a conversation about their child that went really well and to consider what was happening in that conversation that led to its success. As parents volunteer they practice good communication skills (verbal or non-verbal communication strategies). It then becomes easy to see how body posture, eye contact, and facial expressions are non-verbal influences on a conversation.

Most Parent to Parent programs also include time for considering what the role of the supporting parent [illegible] to offer emotional support in encouraging ways, to provide information without [illegible], provide a safe environment for problem solving, be a friend) and is not. Often this discussion is based upon their own [illegible] about the support they received and [illegible] they found helpful and not so [illegible] about that support. Parents always [illegible] information about what to do when a referred parent needs more support than a supporting parent can provide, as well as what they can expect as their match gets under way. **EP**

If you are interested in learning more about the supporting parent training and available resources from Parent to Parent of Vermont, please contact them at: One Main St, 69 Champlain Mill, Winooski, VT 05404; phone: (802) 655-5290; E-mail: p2pvt@together.net; Web site: http://www.partoparvt.org.

Additional information about developing a Parent to Parent program, preparing parents to serve as supporting parents, and best practices in other Parent to Parent programs nationally is available through: Beach Center on Families and Disability, University of Kansas, 3111 Haworth Hall, Lawrence, KS 66045; phone: (785) 864-7600; E-mail: betsy@dole.lsi.ukans.edu.

Betsy Santelli is the Director of Technical Assistance at the Beach Center on Families and Disability.

Nancy DiVenere is the Director of Parent to Parent of Vermont.

Jo Yoder is the Program Director of Parent to Parent of Vermont.

Katie De Carolis is a Support Parent with Parent to Parent of Vermont.

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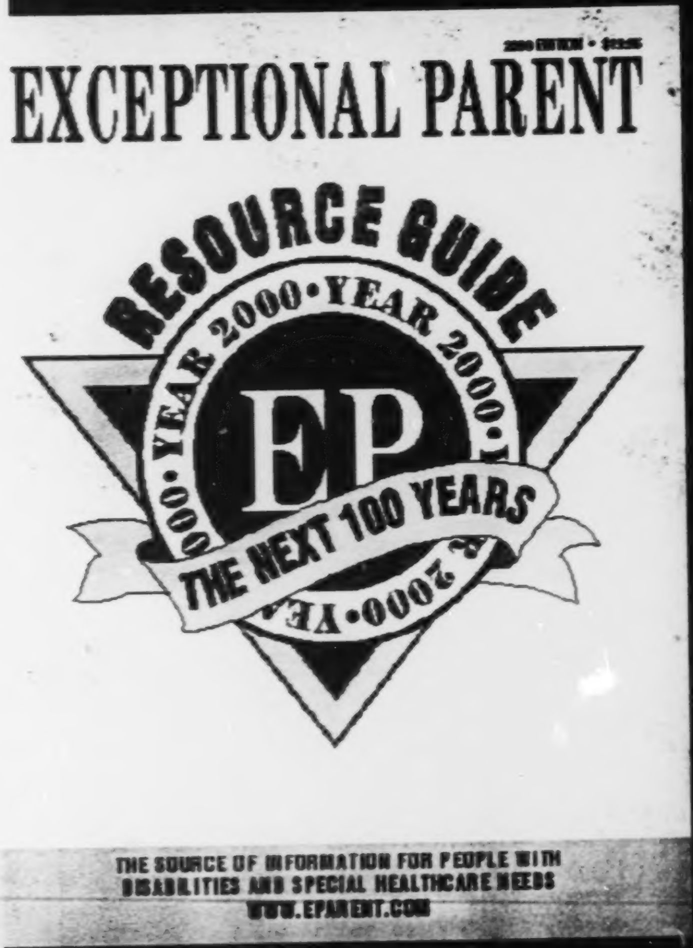
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Part 1

Can We Talk?

PARENTS' PERSPECTIVES ON AUGMENTATIVE AND ALTERNATIVE COMMUNICATION

by Peggi McNairn, Ph.D., CCC/SLP, ATP
and
Cindy Shioleno, M.Ed.

For many children and their families, identifying and obtaining an augmentative/alternative communication (AAC) device is not a simple process. This was the case for Dr. Hal and Christi Urschel and their 4-year-old son, Chance, of Dallas, Texas. Born with holoprocencephaly (a congential defect caused by an extra chromosome), Chance is unable to walk or talk like other children his age. "It has taken almost a complete year to find what is probably the optimal assistive technology solution for our household," reflects Dr. Urschel.

With the realization that their children will require assistive technology, families often enter a world alien to them. This is a world filled with techno-jargon and foreign gadgets.

ASSISTIVE TECHNOLOGY

Before families can understand augmentative and alternative communication systems, they must first look at the big picture of what their children may need. For many parents, this journey begins with the understanding of what assistive technology is and what it can do for their children. One commonly accepted definition can be found in the Individuals with Disabilities Education Act (IDEA), the federal law which was revised in 1997.

According to IDEA, assistive technology is "any item, piece of equipment, or product system, whether acquired commercially off the shelf, modified, or customized, that is used to increase, maintain, or improve the functional capabilities of a child with a disability." Assistive technology can be as simple as a special grip on a pencil or as sophisticated as a high-powered computer system.

"Assistive technology, for us, means anything to help our daughter be more independent," says Laura Warburg of Louisville, Kentucky, mother of 9-year-old Candice. Candice, who has cerebral

Parents of children who use AAC share helpful information, stories, and insights about their experiences with the process of selecting and using communication systems.

palsy, has overcome many obstacles in her short lifetime. "As Candice gets older, she insists on doing things 'by herself!' She's reaching an age, at 9, where she doesn't want mom or dad around to help her all the time. She keeps us moving forward in our search for more and better ways of doing everything. She's still mastering some fine and gross motor capabilities. What didn't work yesterday, many times, will work today."

Assistive technology can be divided into six very broad categories: mobility, positioning, environmental control systems, personal care/leisure, computers (with and without adaptive devices), and augmentative and alternative communication (AAC).

According to the American Speech-Language-Hearing Association (ASHA) in Rockville, Maryland, augmentative and alternative communication "refers to all communication that supplements or augments speech." AAC covers a broad range of techniques and strategies, from simple picture boards to sophisticated, computer-based communication devices with synthetic voices. Other examples of augmentative and alternative communication may include facial expressions, gestures, body postures, eye-gaze, sign language, drawing, and writing.

The importance of communication became evident to the Warburgs when Candice began kindergarten. Laura Warburg recalls that her daughter "was starving for ways to communicate with her classmates, teachers and with even us, her family. Yes, we understood some of what she was able to verbalize to us at that point, but so many times she'd mutter, 'never mind,' and turn away from us after we didn't 'get it' the first few times." The family knew it was time to take action.

"So we began realizing that not only did she have more to say, but that she deserved to be heard!" says Laura. "It was our job to give her access to the tools to communicate with the people in her world—not just with her family and teachers, but with anyone she would meet. Today, she has a DynaVox™ (an electronic communication device) mounted to her wheelchair. She studies for spelling tests with it. She can tell jokes with it. She can use word prediction to compose her own thoughts or she can tell me, her 'programmer,' what she wants me to help her say with it. AAC reinforces her confidence by making her efforts to communicate more efficient."

AAC is most effective when thought of as a "system" for communication rather than as one specific device, piece of equipment, or technique. When taught a variety of communication techniques, a child has a better chance of being successful in communicating his or her thoughts in every situation. Using a "systems" approach avoids the many pitfalls of relying on only one device or technique. The Urschels believe that "the goal of augmentative communication is to allow children to communicate with family members as well as non-family members in all areas of their lives, so that they can share in the richness of multiple intercommunications without having to settle for only being able to communicate part of their thoughts."

EARLY INTERVENTION

Knowing when to use augmentative and alternative communication is almost as complex as understanding what it is. For

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TABLE 1

AAC Team Members

Team Member	Possible Team Role
Administrator	Team coordination and program mission, staff release for training, funding resources
AT/AAC Consultant	Information on AT/AAC resources and device training, ongoing technical assistance
Audiologist	Assessment of hearing acuity, skills, and needs
Manufacturer's Representative	Device information, demonstration, and training
Paraprofessional/Aide	Communication needs, device programming
Occupational/Physical Therapist	Positioning, mounting, and access issues
Physician/Nurse	Medical information
Psychologist/Assessment Personnel	Information on cognitive and academic skills
Speech/Language Pathologist	Information on language and communication skills, ongoing implementation and development of system
Teacher	Identification and implementation of curriculum and classroom communication needs
Vision Specialist	Information on visual acuity, skills, and needs
Vocational Counselor/ Transition Specialist	Vocational testing and counseling, funding information

continued from page 73

some children, AAC may be their primary means of communication. Others may use it to clarify and expand their speech. Regardless of why the child uses AAC, developing a communication system at an early age is imperative.

Accepting that a child needs an augmentative communication device may be difficult for some families for many different reasons. This was true for the Warburg family. "I've heard many parents and teaching professionals voice their fear about AAC inhibiting speech development. Personally, that was never one of our excuses in the early days of our denial about AAC," says Laura Warburg. "Our denial stemmed from being overwhelmed with all the physical aspects of cerebral palsy and Candice's lack of consistent ability to make a selection between two pictures. We wanted instant gratification. Her interest and her laughter served as the instant gratification we needed at the time. She has a belly laugh that is unbelievably contagious. It was a passive and contented existence for a while. Looking back on these early days, I think it would have taken a knowledgeable AAC friend to 'camp out' with us in real life (as opposed to observing in therapy sessions) for more than just an hour a week to have convinced us of other needs and possibilities."

In reflecting on those early years, Laura believes, "It's never too soon to introduce AAC to a family. AAC introduction plants a seed. It may take a long time for it to take root or it may start to grow immediately. All families come with different dynamics. It's important for professionals to get an idea about daily life."

> **"It's never too soon to introduce AAC to a family. AAC introduction plants a seed."**

THE TEAM PROCESS

Because the selection, operation, and use of augmentative communication systems requires input from more than one discipline, the use of a "team approach" is essential. Although the concept of using a team to deliver AAC services is not a new one, the reauthorization of IDEA requires key decisions to be made by teams for school-aged children. This team, in which the parents play a vital role, is one of IDEA's greatest strengths—as well as one of its greatest challenges. Unfortunately, many families still do not have access to assistive technology teams. "We never had one," says Laura Warburg. "Still don't. It's more like creative existence—being in the right place at the right time and asking the

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right questions of the right people."

Augmentative communication teams may function in either a multidisciplinary, transdisciplinary, or interdisciplinary capacity. According to ASHA, these three basic types of teams differ in how team members interact one another and in how services are delivered.

Within a multidisciplinary team format, different specialists from several areas of expertise provide services in isolation from each other, evaluating and implementing results and recommendations independently within their respective areas. The results of this type of team format can be fragmented and misleading.

> **Core team members would ... interact frequently with the child in multiple environments such as school, home, and the community.**

With a transdisciplinary team format, one professional on the team assumes primary responsibility for direct services, while still consulting with professionals from other disciplines. This type of team format encourages professionals to cross traditional disciplinary boundaries and acquire knowledge of related disciplines that is then incorporated into their assessments and services. The disadvantage to this model is that children who require augmentative and alternative communication often have complicated and multifaceted needs. These children often require a higher level of expertise than any one professional can provide.

The third team approach, interdisciplinary, is typically composed of individuals who possess expertise in widely divergent areas. Unlike the multidisciplinary or transdisciplinary teams, a formal mechanism exists so that information is shared among the team members, and decisions are based upon this shared information. With this team approach, it is acknowledged that no one person or professional has adequate training or expertise in all of the necessary areas. As a result, team members, including the child and family, are involved with the entire process, sharing joint ownership, responsibilities, and outcomes.

TEAM MEMBERS

Identifying who should serve as a team member is one the first steps in building an effective AAC team. Deciding who should serve on the AAC team is dependent on many factors, including the needs of the child, the location of the team (hospital-, community-, agency-, or school-based), the type of information needed, and the supports that are required. Team members may include: parents, administrators, therapists, teachers, medical personnel, and AAC manufacturers. Table 1 lists a few of the possible team members and their roles and responsibilities.

While this list of potential team members may seem overwhelming, not all decisions must be made by the entire team. Including all potential team members in every decision may create a team so large that it has difficulty functioning. One strategy to control team size is to establish a core AAC team. Core team members would then interact frequently with the child in multiple environments such as school, home, and the community. Subgroups would be established and used on an "as needed" basis. The Urschels reported that, in addition to their regular therapists, "working with consultants in the speech, language, and assistive technology areas was extremely helpful." It is important that the team stay focused and committed to the common goal of assisting the child to become a successful communicator.

The level of expertise or skill that each member brings to the team may vary greatly. No one person can be expected to know or possess all the skills necessary for every AAC consumer. Many times, team members learn or acquire important skills during the assessment and implementation process. Other times, AAC consultants from other agencies may work with team members to complete the assessment and implementation process. Regardless of ability level, the key to success is for all team members to be aware of resources available and how to access those resources when needed. **EP**

The authors welcome questions and comments.

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ABOUT THE PARENTS:

Dr. Hal and Christi Urschel live in Dallas, TX, with their 4-year-old son, Chance.

Frank and Laura Warburg live in Louisville, KY, with their 9-year-old daughter, Candice, and 6-year-old son, Joey.

THE NATIONAL PERINATAL ASSOCIATION

Perinatal means "surrounding the time of birth" —a great time to be healthy!

The National Perinatal Association (NPA) is an association comprised of individuals and organizations concerned with perinatal health issues, from preconception through infancy, within a multicultural perspective. Their mission is to work toward the common goal of better healthcare for mothers and infants through education, research, and advocacy. The NPA relies on its members—healthcare consumers and professionals from across the spectrum of disciplines—to work together and help carry out its mission.

NATIONAL
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NPA

One of their goals is to help construct a framework for national advocacy, and, by getting many different disciplines involved, create a greater understanding and a greater impact.

What Membership in the NPA Offers Parents

The NPA remains committed to the active inclusion of parents in all health decisions made about their children. According to NPA's Executive Director, Sheila S. Sorkin, "Parents and infants are the centerpoint of all perinatal care concerns." Ms. Sorkin says that parents may benefit from participation in the NPA's Annual Clinical Conference, where they can learn about products and services available, as well as information sessions, which include "Models of Care."

The NPA also considers individuals (family members) eligible for their annual awards program. Recently, the NPA recognized Julie Gordon, the mother of a child with special needs and founder of MUMS (Mothers United for Moral Support, Inc.), now a national support organization for parents or care providers of children with birth defects, chromosomal abnormalities, or rare medical conditions.

In addition, parents are invited to contribute to the NPA bulletin, serve as members of the various NPA committees and ultimately, sit on the Board of Directors. All NPA members receive a quarterly bulletin, which features articles on clinical care and research, advocacy, community service and maternal child health career development. Reduced-rate subscriptions to relevant magazines are another membership benefit.

Ms. Sorkin reports, "As a multidisciplinary association, the NPA has always included consumers in its programs and services. There is a renewed effort in outreach, which has been accomplished through the establishment of networks." She points out that the NPA's role as a sponsor and member of the planning committee for the upcoming World Congress and Exposition on Disabilities (see *Editor's Desk* for more information) will allow the group to have access to an even wider audience. "Through this effort, NPA has been introduced to other organizations whose mission is to serve caregivers. Families involved in perinatal issues often become caregivers. It is a wonderful opportunity for NPA to improve communication with such organizations."

Ideas into practice

Currently, the NPA is involved in numerous projects such as:

- Production of a monograph entitled "Transcultural Aspects of Perinatal Health Care" is under way. This monograph is for maternal and child health practitioners, educators, and perinatal specialists to help them care for mothers and their families in a way that is more sensitive to cultural background.
- "Models of Care" is a publication produced by the NPA for community, health, and service organizations.
- In 1999, the NPA organized a Summit Conference, a collaborative effort by 21 national maternal and child health organizations. Out of the conference proceedings came a monograph entitled, "Shaping the Future of Perinatal Health Care."
- NPA's Annual Clinical Conference provides education and networking for physicians, registered nurses, social workers, certified-nurse midwives, nurse practitioners, dietitians, educators, consumers, public health and health services workers, administrators, and multidisciplinary perinatal professionals.
- NPA leaders serve on the "Friendly Access" National Advisory Board. Friendly Access is a program providing quality perinatal care for low-income mothers run by the Lawton and Rhea Chiles Center for Healthy Infants, Mothers, and Babies. **EP**

To receive a membership brochure detailing the many benefits of membership, contact:

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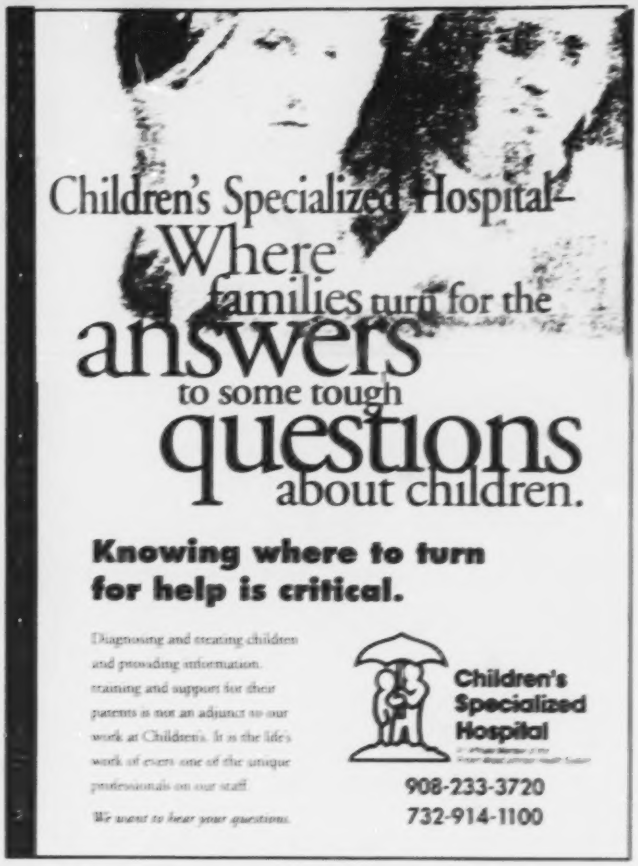
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FAMILIAR FACES

Hannah Danielle Moon, 3, loves to help out in the kitchen! Hannah, who has cerebral palsy, attends preschool three days a week. She loves her teacher and friends there. Some of her favorite activities are swimming, telling ghost stories, and helping her Mom cook. Hannah lives with her parents, Wayne and Kellie, in Oxford, AL. Hannah is looking forward to becoming a big sister on Valentine's Day.

Say Cheeseburger! **Wendell Fletcher Wood**, 4½, has CHARGE association, a rare genetic disorder. Wendell was born with a defect of the left eye, profound deafness, ear abnormalities, facial palsy, repaired heart defects, genital hypoplasia, and vocal cord paralysis, and needed a feeding tube. He has received Electronic Stimulator Therapy. Wendell has since had his tube removed, and a week later enjoyed his first burger and fries. Wendell loves Scooby-Doo and playing with his siblings. He lives on a farm in Clarence, MO with his parents Wendi and Lee, sister, Gretchen, 6½, and brother, Riley, 3.

Joshua (Joshy) William Kahrmann, 8, is all smiles! Joshy was diagnosed with Leigh disease. He attends Beaver Acres Elementary School, where he enjoys listening to stories, walking in a gait trainer, and scooting around in his adaptive chair. Joshy also loves upbeat music, like Disney songs. Joshy lives in Aloha, OR, with his Mom, Traci, Dad, Bill, and little brother, Michael, 3.

Would you like to share a favorite candid snapshot or slide of your child and/or family with other readers of *Exceptional Parent*? Send it to: Readers' Photos, *Exceptional Parent*, 555 Kinderkamack Road, Oradell, NJ 07649-1517. (Please do not send originals or "one-of-a-kinds" as we regret that photos cannot be returned.)

Two smiles are brighter than one! Twins, **Caanan and Jordan Williams**, 8, pose for a portrait with their stepmother, **Octavia Paul**. Caanan and Jordan were born premature, and both have cerebral palsy, shunts, mental retardation, and hydrocephalus. Caanan, who has seizures but is mobile, loves to dance and listen to music. Jordan has limited mobility and uses a wheelchair and loves to watch sports on TV. The twins attend public school and love to play together. They live in Dallas, TX with their Dad, Patrick Glenn and stepmother.

Benjamin Richard Lallak, 2, who has spastic quadriplegic cerebral palsy, has a smile that will melt your heart. He loves being outdoors, swinging on his swing set, and going for walks through the woods in his stroller with his Mom, Melissa, and Dad, Jeffrey. He has two cats, who walk right under his hands so he can pet them. Benjamin attends a daycare center with an aide. His family describes him as a determined and strong-willed little boy. Benjamin and his family live in International Falls, MN.

According to Grandpa William Cleghorn, his granddaughter **Savannah Lynne Cleghorn**, 6½, is "the joy of our lives." Savannah was born 3 months premature and was diagnosed with spastic quadriplegic cerebral palsy. She uses a wheelchair to get around and attends first grade. Savannah loves Saturday morning cartoons, computers, chicken nuggets, and camping with her brothers Mark, 9, and Joe, 11, her parents Victoria and Michael. She has weekly therapy and receives botox injections three times a year. She lives with her family in Las Vegas, NV.

On a separate sheet of paper, write your child's full name, age at the time the photo was taken, address and daytime phone number. Please identify everyone in the photo. If you like, you can also write a few sentences about your child. Then look for a familiar face in an upcoming issue!

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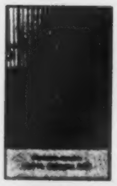

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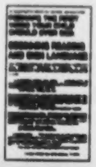

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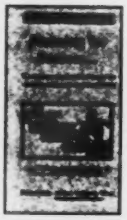

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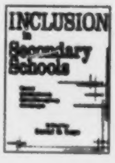

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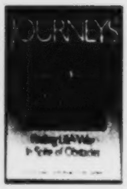

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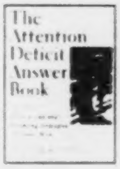

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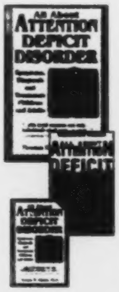

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MAKING TRACKS

by Jennifer Hester

Looking for a way to get your family outdoors this winter? You might try snowshoeing—an increasingly popular sport that is inexpensive, does not require a lot of specialized equipment, and can be done just about anywhere there is snow.

Snowshoes have been around even longer than skis. The first snowshoes were made of wood and leather, designed for trips or hauling things over the snow. Today's equipment is lighter and ideal for everything from casual walks or hikes, to overnight trips in the woods. "It's a great activity for families because it's inexpensive, and you can use snowshoes on just about any kind of terrain," says Billy Giblin, Nordic program coordinator for the National Sports Center for the Disabled in Colorado. "Try Nordic centers, golf courses, national, state and city parks, or downhill ski areas."

Anyone who can walk can snowshoe. The sport is a great choice for fun and fresh air and is accessible to people with many different disabilities.

Adaptive snowshoeing can be a low-cost adventure for the whole family

Going snowshoeing in parks requires only the cost of admission to the park, and access to most public lands, like national parks or forests, is free. If you want to try a groomed trail for your first snowshoe experience, try a Nordic center. Most centers charge a trail fee, which can range from $5 to $20.

Anyone who can walk can snowshoe, making it a great sport for children who have disabilities like visual and hearing impairments, amputations, brain injuries and developmental disabilities. If your child uses a wheelchair, try a close cousin to snowshoeing, cross-country sit-skiing. Manufacturers make cross-country sit-skis that use poles and arm power to propel the skier across the snow.

Nancy Brigham of Denver, Colorado, and her son, Colin, who has a developmental disability, have been avid snowshoers for several years. Nancy notes, "It's a nice way to get out into the snow without a lot of technique, especially if they have a problem with balance. It would be a good way of getting everybody with different levels out together."

TIPS for putting your best shoe forward

The first time you use your snowshoe equipment, try flat areas like roads. Then try deeper snow and hills. "Going up a hill, people may not be used to stepping in deep snow. Set your feet in. Plant your foot well and then move to the next step," says Giblin. "Make every step count."

When you are going uphill, do not bend too far forward. Stay upright on the snowshoes, to be sure they do not slip out from under you. "Initially walking downhill, keep your speed checked," says Giblin. "Stay on top of the snowshoes and just relax. Do not lean too far back, and keep your joints loose. If the hill is too steep for you, go in zig zags down the hill."

PHOTO BY KIEFEL SPORTFOLIO AND THE NATIONAL SPORTS CENTER FOR THE DISABLED

How to keep your snowshoe trip safe and comfortable:

- Layer your clothing. Snowshoeing is an aerobic exercise, and you will need to add and remove layers throughout your trip to keep comfortable. Remember, wet cotton does not insulate. Try wool or synthetic fabrics.
- Take breaks to drink fluids and eat snacks. You will be using lots of energy on your trip, and you need to stay hydrated even in cold weather.
- Protect your eyes from the sun. Glare off the snow can be damaging even on cloudy days, so wear sunglasses.
- Be sure someone knows where you are going and when you will be back.
- Be sure you are familiar with where you are going. Do you need to take a trail map?
- Take turns leading, especially in fresh snow. Breaking a trail can be tiring.
- Be aware of changing weather conditions, especially in the mountains.
- Take the time to learn about avalanche safety before your trip if you will be in avalanche country.

Easy outfitting

Snowshoeing has been called one of the hottest sports of recent years, probably because it is so easy to get started. There is no need for fancy clothes, expensive lessons, or difficult techniques.

Snowshoes typically have four parts: bindings, frames, decking, and claws. Bindings attach the snowshoe to your boot. Most bindings use a system similar to laces. Look for something that will be easy to work with in gloves or with cold hands. Frames are made of wood or metal and give the snowshoe its shape and size. Most modern snowshoes have lightweight aluminum frames. Decking is the material inside the frame that lets you "float" on the snow. Claws on the underside of the snowshoe give you traction on icy slopes. Most are at your toe and heel and are similar to crampons.

"A lot of manufacturers are making a good variety of small snowshoes for kids," says Giblin. "You can get a new pair of snowshoes for as low as $100, and most outdoor shops supply rentals. You can also look for used equipment in second-hand stores."

You can wear snowshoes with anything from sneakers to hiking boots. If your child wears cants in regular walking shoes, you can also cant the boots he or she will wear to the snowshoe. Poles are optional equipment for snowshoeing that can help children with balance problems. Some snowshoers use just one pole.

Snowshoeing is a great way to work the hamstrings, which can prevent knee and back injuries. It is also a good aerobic workout; snowshoes can get your family on the snow at a pace ranging from walking to running. The pendulum motion of your arms while snowshoeing makes it an upper-body exercise.

Snowshoeing is a confidence-building winter sport for many children. Because snowshoes have claws that grip the snow, children (and adults!) are less worried about slipping and falling than with sports like skiing. Brigham says Colin, 18, had been a skier for years. But as he got older, he grew more afraid of falling.

"He was getting so rigid on the slopes," she says. "I figured he needed to learn to move his body more. And as he got older, he was getting more afraid of falling. Plus, snowshoeing was cheaper. That's a nice thing about making it a family activity—it's economical. Plus you can do it anywhere." **EP**

Outdoor activities like snowshoeing are great opportunities for families to spend time together.

PHOTO BY KEEFEL SPORTFOLIO AND THE NATIONAL SPORTS CENTER FOR THE DISABLED

If your child uses a wheelchair, try a close cousin to snowshoeing, cross-country sit-skiing. Cross-country skiing is excellent aerobic exercise for both standing and sitting skiers.

PHOTO BY JEFF STINE/NATIONAL SPORTS CENTER

Jennifer Hester is the Media and Public Relations Manager for the National Sports Center for the Disabled in Winter Park, Colorado. The National Sports Center for the Disabled offers snowshoeing, snowboarding, and downhill skiing for children and adults with disabilities. For more information, contact the Center at PO Box 1290, Winter Park, CO 80482; telephone: (970) 726-1540; fax: (970) 726-4112; or visit their Web site at http://www.nscd.org.

CYSTIC FIBROSIS

What is it and what does it mean for your child?

By Preston W. Campbell III, M.D.

Take a deep breath. Hold it in. With your lungs filled, use a straw to breathe with the remaining space in your lungs. This is only the beginning of what it feels like to have severe lung disease, and cystic fibrosis (CF) is a prime example.

CF causes the body to produce abnormally thick and sticky mucus in the lungs and other organs. This mucus clogs the airways and provides a breeding ground for life-threatening lung infections. It can also block the duct from the pancreas to the small intestine, thus reducing or eliminating a person's ability to digest food. CF produces a number of symptoms such as very salty-tasting skin, recurrent pneumonia, failure to thrive, and chronic wheezing or coughing.

CF is a genetic disease inherited from *both* parents, just as one inherits hair color or eye color. In other words, for a person to have CF, he or she must inherit two defective copies of the CF gene—one from *each* parent. More than 10 million Americans are symptomless carriers of the defective CF gene.

There are approximately 30,000 individuals who have CF in the United States today. Currently, the median age of survival for a person who has CF is 32 years. New treatments and promising research, however, give us hope that many children born today who have CF may live into their 40s or 50s or beyond.

Q What does CF mean to my child?

A People who have CF have special healthcare needs including:

- special diets to ensure proper nutrition and growth;
- medications to counteract the effects of the disease, including replacement enzymes to help digest food; and
- chest physical therapy to help loosen and dislodge the thick and sticky mucus from the airways.

Most people who have CF can lead normal lives apart from these daily treatments. Most children who have CF grow up to attend school, have friends, and take part in regular sports and hobbies. Many adults who have CF marry and have families.

Parents of children who have CF should raise them with the same expectations and rules that they apply to other children. Having CF should not stop anyone from becoming a contributing member of society.

Q What can I do to make sure my child who has CF is in the best possible health?

A One of the most effective ways to make sure people who have CF are getting the best care is to encourage them to receive treatment at one of the more than 110 Cystic Fibrosis Foundation-accredited care centers across the United States. These centers provide specialized care using a multidisciplinary team approach. Teams of physicians, nurses, dietitians, and social workers are adept at recognizing and treating the unique healthcare needs of the person who has CF. This specialized medical care has been noted as one of the primary reasons why the median survival age for people who have CF has risen steadily for more than three decades.

Because CF affects the lungs, there are some other common-sense considerations that should be observed. People who have CF:

- should not smoke or be exposed to second-hand smoke;
- should have access to specialized CF healthcare;
- should strictly comply with the treatment regimen prescribed by their CF physician; and
- remain optimistic about new treatments and promising research.

Q What does a CF diagnosis mean financially?

A It is wise to learn as much as possible about managing medical expenses for CF care. Parents should comb through the details of their insurance plan and familiarize themselves with what is covered and what is not. The insurance policy should cover specialized medical care provided by CF specialists at CF Foundation-accredited care centers. Access to specialty care is critical for people who have CF and is a contributing factor in increasing both the quality and length of their lives.

There are also a number of state and local programs designed to help parents and adults deal with the expenses of diseases like CF. These

Ask the Doctor addresses issues of concern to our readers and is usually coordinated on a monthly basis by David Hirsch, M.D., a pediatrician and member of *Exceptional Parent's* Editorial Advisory Board. Dr. Hirsch is a partner in Phoenix Pediatrics, Ltd., in Phoenix, Arizona, and specializes in treating children who have developmental disabilities and chronic illnesses.

Parents should review any suggestions made in this column with the appropriate professionals. Mention of specific products or medications illustrate suggestions and are not endorsements of any specific products.

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include Medicaid and programs for children and adults with special health needs. Because these programs vary from state to state, the CF Foundation recommends that individuals call the social worker at their CF care center to learn what programs and laws may apply to their needs.

To help offset the costs of CF medications, the CF Foundation established CF Services, Inc., a national mail-order pharmacy. This pharmacy provides medications to people who have CF, usually at significantly reduced costs, and makes a determined effort to work with all insurance companies and public programs, such as Medicaid.

Q What research is being done to help people who have CF?

A Because CF is a complex disease, the CF Foundation takes many approaches to treating and curing it. The CF Foundation supports cutting-edge research aimed at finding new ways of treating this devastating disease. In fact, there has been so much progress in understanding CF that the CF Foundation has launched a nationally acclaimed drug development program to help transfer the findings of laboratory science into new CF drugs as quickly as possible.

Such efforts by the CF Foundation and CF researchers around the world have led to a number of experimental treatments that are now entering clinical trials. These new treatments strive to treat every aspect of the disease. For instance, some drugs "fix" the "inner machinery" of cells affected by CF. Other experimental antibiotics may give physicians entirely new approaches to helping people who have CF fight life-threatening lung infections. Finally, another treatment, called gene therapy, actually attempts to replace the defective CF gene with a healthy one. The overall goal of all of these experimental remedies is the same: to increase the quality and length of lives of people who have CF. These promising new treatments must first be proven safe and effective before the Food and Drug Administration approves them for treatment of CF.

Q When will there be a cure?

A No one is able to say when there will be a cure for CF. Today there is more hope for people with this disease than ever before. Some of the best scientists and physicians in the world are devoting their lives to curing this disease. Today, largely because of the tremendous contributions of these individuals, who are often supported by Cystic Fibrosis Foundation research grants, much has been learned. Most important, each new discovery brings us one step closer to the cure. **EP**

Preston W. Campbell III, M.D., is a pediatric pulmonologist and former director of the CF care center at Vanderbilt University. He currently serves as the Executive Vice President for Medical Affairs for the Cystic Fibrosis Foundation in Bethesda, MD.

For more information on CF research, programs and services available to people who have CF, including the CF Services, Inc., Pharmacy, please visit the Cystic Fibrosis Foundation's Web site at www.cff.org; or contact them at the National Office at 6931 Arlington Rd., Bethesda, MD 20814; or call (800) FIGHT CF.

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Circle #21

SWIMMING IN CYBERSPACE

by Daniel B. Kessler, M.D.

Recently, I participated as a guest expert in a live "chat" discussion on the Internet on attention deficit hyperactivity disorder (ADHD). As a father of two children and a pediatrician who uses the Internet for professional and personal correspondence as well as for research, I was certainly familiar with it. Now I had an opportunity to be the guest expert on a Web site chat. I would be the one to whom everyone would be asking questions, and I was not certain that I wanted to jump into those waters. Ultimately, after discussing the nature of the live chats sponsored by Eparent (www.eparent.com), the Internet version of Exceptional Parent Magazine, and Parent Soup, the parenting division of iVillage.com, the Women's Network, I decided to take the plunge.

In all, I have now done two live chats and survived, and even enjoyed, the experience. Both were discussions on ADHD, an area I have some comfort talking about. A Chat coordinator reviewed my background and credentials and I was all set as the expert.

Come on in—
the water's fine!
My experience with a "live chat" on the World Wide Web

How to Chat

In order to participate in the chat, I needed to download special software into my computer from the chat's Web site. Then the "chat room" opened for business. Upon entering the chat rooms, each person's "chat name" appears both on the "chat board" and on a running list of names of everyone else in the chat room.

Chat names, which do not have to be a person's real name, are the screen names that people use upon joining a chat room. After entering the room, chatters are welcomed by the host. The host informs participants—who are welcome to come and go as they please during the chat—of the topic and who the guest expert is. The chatters are instructed to indicate that they have a question for the expert by typing in a question mark from their keyboard. This mark appears beside their "name" on screen and alerts the host that they have something to ask. The host contacts each participant individually, forms a "queue," or line-up, of participants with questions, and calls on them one at a time. Using this "private messaging" capability, the host asks each chatter to have his or her question typed in and be ready to hit "enter" on the keyboard when his/her turn comes. This keeps the chat flowing at a reasonable pace. Likewise, the expert is supposed to be signaled by the host as to whose question is to be answered next. The expert informs the host when finished with an answer and ready for another question.

In my first experience, people just jumped in and asked their questions or "talked" to each other, greeting each new person entering, saying goodbye as they left the chat room or as they commented on questions. The second time around, after speaking with the Chat Coordinator adn accepting his help and suggestions, I was much better at managing the questions, accepting the help and suggestions of my hosts. I think everyone else enjoyed it as much as I did. All in all, it is not a bad way to spend some educational and fun time. Now I am actually looking forward to my next live chat.

If you find yourself interested in participating in a chat, I would suggest the following guidelines to get the most out of the experience:

- First, learn something about the organization or group sponsoring the chat. Organizations generally provide that kind of information on their sites. Is the organization endorsed by other respected professional groups? Do they provide background material on the topic being discussed? What about the "expert?" What are his or her professional credentials? Is he or she credible? Is it someone you would feel comfortable bringing your child to see?
- It is always a good idea to get to the chat area early because chat rooms can get quite busy. Checking in early with the moderator gives you a better chance of getting the expert to answer your question.
- When asking a question, send it to the moderator with a question mark at the beginning of the message. An expert-led chat is like a question-and-answer session at the end of a lecture. Wait your turn to ask your question. This way, the expert will be able to focus on your question and give you a well-thought-out answer. If you wish to have a side conversation during the chat, use the private messaging system that is available in most chat rooms.
- After the chat, you may be directed to another chat or to a Web site with more information on that topic.
- No matter what you learn from a chat, always review any information or at least discuss it with your child's physician before taking any action. **EP**

Daniel B. Kessler, MD, is Director of Developmental and Behavioral Pediatrics at the Children's Health Center of St. Joseph's Hospital and Medical Center in Phoenix, Arizona. He is also a Clinical Associate Professor of Pediatrics at the University of Arizona College of Medicine. Dr. Kessler's article, "Problems of Behavior and Learning: A Pediatric Perspective" appeared in the June 1998 issue of Exceptional Parent.

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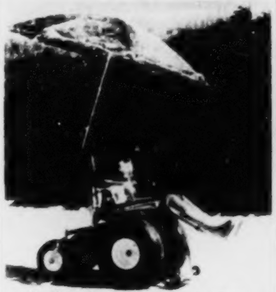

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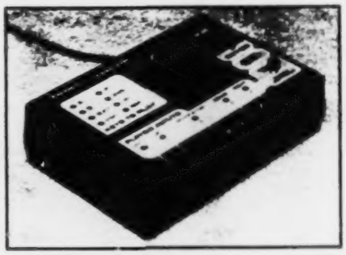
This electronic pre-reading tutorial program is designed for use by children between the ages of 4 and 7 years with cognitive and learning disabilities. The mailbox-shaped device uses Leap the Frog to teach the alphabet, phonics, rhyming, and reading comprehension. It also introduces sentence creation, grammar, and early reasoning skills. This talking toy uses three AA batteries, includes 26 talking postcards (one for each letter of the alphabet), and offers three modes of play with six puzzles and games: Object/word identification, spelling, and rhyming. Also included are fun music and sound effects. The unit's face also includes three-dimensional lower case letters of the alphabet. Other standard features include volume control and automatic shutoff.

LeapFrog™ (A Division of Knowledge Kids Enterprises) 1250 45th St., ste. 150, Emeryville, CA 94608; (800) 701-5327

TEAM XTREME™



Team Xtreme™ is designed to enable individuals with upper extremity disabilities to play video games on Nintendo game systems. The unit plugs into the Nintendo system and enables the player to independently play the video games using up to five switches (not included). Each switch can be set up to individually control any key found on the standard game controller and a single switch can also be set up to control two keys simultaneously, allowing two functions, such as moving up and to the right, to be accomplished at the same time. A standard game controller can also be plugged into the unit to allow another individual to be "teamed" with the player to provide assistance when needed. The actions of the teamed players are treated as a single player by the game system and can be adjusted with a switch. The unit also features a connector, enabling commercially available joysticks or ganged switches to be used in addition to four individual switches.

Pathways Development Group Inc. 17409 57th Ave. West, Lynnwood, WA 98037; (877) 742-4604

QCHORD™

The QChord™ Digital Songcard Guitar is an electronic music synthesizer designed for use by children and adults with fine motor disabilities. The device enables the player to make music simply by pressing buttons and moving one hand over the strum plate. This unit features a strumplate that strums like a guitar and a push-button keyboard that plays a range of chords or a melody like a keyboard. The unit, which can be powered with batteries or a plug-in adapter, also features more than 100 instrument voices (acoustic guitar, grand piano, harpsichord, violin, sound effects, etc.) and 10 rhythms (rock, march, waltz, etc.). QChord™ offers multiple skill levels that add more features as players become more proficient.

Suzuki Corporation PO Box 261030, San Diego, CA 92196-1030; (800) 854-1594; http://www.qchord.com.

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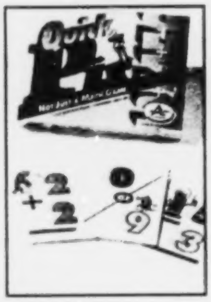

Designed for use by children (age 7 and up) with learning disabilities, this math skills game teaches addition and subtraction skills. The game comprises a set of "answer cards" to be dealt between two to four players. The answer cards are to be paired with the matching question cards as they are turned up one at a time. The goal is to match the correct answer to the matching math question card as quickly as possible and capture the card pairs.

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Safety 1st, Inc. 45 Dan Rd, Canton MA 02021; (800) 723-3065

The ABLEDATA database of assistive technology and rehabilitation equipment contains information on more than 25,000 products for persons of all ages who have a physical, cognitive, or sensory disability. Products are chosen for this page by the ABLEDATA staff based on their specific applicability to or design for children who have disabilities. ABLEDATA, operated by Macro International Inc., is funded by the National Institute on Disability and Rehabilitation Research under contract number HN-96015001.

For more information on these and other assistive devices, or to submit product information for the database (and possible inclusion on this page), contact: **ABLEDATA, 8401 Colesville Rd., Ste. 200, Silver Spring, MD 20910; (800) 227-0216 or (301) 608-8998 (voice); (301) 608-8912 (TTY); (301) 608-8958 (fax); Web site: http://www.abledata.com.**

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Children's Page

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Fighting the Ultimate Battle

by Jonah Gillian Bea-Taylor

Mom's Turn:

My son, Jonah Bea-Taylor, is attending Emory University as a freshman this fall. He wrote the following piece for his essay requirement for admission. I believe it reveals one of the many complexities "exceptional" siblings have to face.

Once upon a time, my brother and I played at fighting great battles. We chose our weapons carefully; his sword was wooden, mine plastic. Our arena was the driveway. His chariot was an electric wheelchair, mine was a scooter. We clashed and spun, and both died several times over. We were equal warriors; there were no differences between us.

I was not troubled that people always asked about him. It seemed normal that I was often the only one who understood his speech. Yes, I was sometimes surprised when people stared at us in public places, but most of the time I forgot that he was different.

Jonah, then 15, gives Micah, 10, a helping hand. Below left: The brothers take a break from cycling. Left to right: Mom, Judith, Jonah, and Micah share a smile.

My brother, Micah, has cerebral palsy and is both physically and mentally challenged. He uses a wheelchair and can do very little without assistance. Moving Micah through a world designed for "normal" people is often difficult. Even going to the movies can be a tremendous challenge.

The greatest difficulty for me, however, is my conflict surrounding his care. Some families that have a child with disabilities give many responsibilities to the siblings. My parents, on the other hand, shouldered the burden. They left me with the responsibility to treat Micah like any other brother. We played games, watched movies, and traveled together. My parents took care of his daily needs. I never had to go through the ordeal of taking him to the bathroom, and I rarely fed him at dinner.

It was not my duty to care for my brother, so I was unprepared to truly help when his needs became more demanding. As Micah grew bigger, we could no longer carry him up a flight of stairs. Simply transferring him from the bed to his wheelchair required a significant effort. We hired aids to help, but at times even they experienced difficulties. The constant effort wore on everyone. Micah could never be left alone. Someone always had to be there to lift him, to feed him, to pick things up for him, or to pick him up when he fell over. Suddenly I was needed, but I felt uncomfortable. If only I could say that it felt like a natural progression—that I would have done anything for my brother—that it was not an annoyance to watch him when Mom went out.

Even now I wish I could say that I am willing to make whatever sacrifices are necessary when he needs my help, but I cannot. Perhaps it is selfish, but it would be worse not to acknowledge the resentment the responsibility creates. Still, I feel that I am not devoted enough. I have this rosy vision of what a brother in my situation should be: one who gives his brother everything; one who supports him in all areas, and one who defends him against a world unable to embrace diversity.

I want to help my brother win his battle, but I am not yet a great enough warrior. I am still learning how to fight for myself. I hope to one day solve my internal conflict so that I can stand beside my brother when he needs me. I do not know what the future holds, but I know Micah and I will both grow in our own ways. I know that my understanding of life is profoundly changed. **EP**

Jonah, 19, Micah, 15, and Mom live in Palm Beach, FL.

The Children's Page welcomes contributions from children who have disabilities, their siblings, and their friends. Be creative! Send your stories, photos and/or artwork to: **Children's Page,** *Exceptional Parent,* 555 Kinderkamack Road, Oradell, NJ 07649-1517. **Be sure to include your name, address, and day-time telephone number!**

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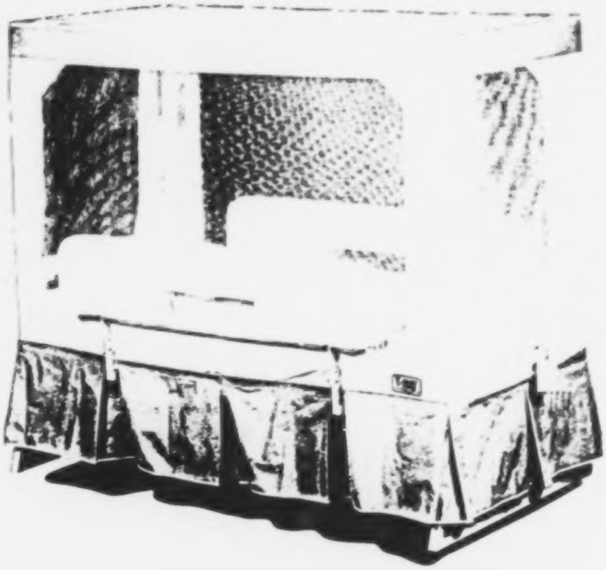

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Brain Awareness Week is a worldwide partnership between the Dana Alliance for Brain Initiatives and hundreds of national and international organizations. During this year's event, starting March 13, 2000, visit our site at **www.dana.org/brainweek.** When you get there, you'll see how far we've come in understanding the complexities of our brains - and what exciting discoveries await us in the future.

Here's what you'll find.

Calendar: Search for local community events such as lectures, exhibits, school programs and more.

Partners List: Find out who's partnering with the Dana Foundation during Brain Awareness Week. You'll be surprised at the list of over 900 national and international organizations, and you can link to many of them.

Education: This section contains educational resources for children, parents and teachers. You'll find brain-related materials and links to organizations with sites offering valuable tools for home and classroom use.

Puzzles: Download a brain-teasing variety of puzzles and games for children and adults alike.

Graphics: This section includes posters, flyers and logos for Brain Awareness Week.

Community Outreach: Find information on how to plan public programs for Brain Awareness Week. You'll find suggestions about selecting a topic; finding a speaker; the do's and don'ts of writing for the public; and how to plan a media campaign. Plus, you'll see links to publications that offer helpful scientific brain-related information.

So get involved. Start to learn more about your brain, and use us as a resource. This could be one week that changes your whole life for the better.

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- poor muscle tone
- seizures
- low levels of activity
- developmental delay
- slow growth

Conditions Associated with Increased Risk for Developing Carnitine Deficiency:

- fatty acid oxidation defects
- mitochondrial myopathy
- dialysis
- premature birth
- administration of carnitine- free TPN
- treatment for HIV—especially administration of zidovudine (AZT)
- administration of valproic acid
- administration of pivalate derivatives
- administration of emetine
- administration of sodium benzoate

Adverse events reported with Carnitor® use include nausea, vomiting, body odor, gastritis, and seizures. There are no reported contraindications or warnings. Please refer to the adjacent brief summary of prescribing information.
For intravenous use only.

CARNITOR® (Levocarnitine) Injection 1 g per 5 mL and 500 mg per 2.5 mL. FOR INTRAVENOUS USE ONLY. Brief Summary of Prescribing Information. (Please see package insert for full prescribing information.) **Description:** Levocarnitine is a carrier molecule in the transport of long chain fatty acids across the inner mitochondrial membrane. CARNITOR® (Levocarnitine) Injection is a sterile aqueous solution containing 1 g of levocarnitine per 5 mL ampoule and 500 mg of levocarnitine per 2.5 mL ampoule. The pH is adjusted to 6.0 - 6.5 with hydrochloric acid. Chemically, levocarnitine is (R)-3-carboxy-2-hydroxy-N,N,N-trimethyl-l-propanaminium hydroxide, inner salt. It is a white powder with a melting point of 196-197°C and is readily soluble in water, hot alcohol, and insoluble in acetone. The pH of a solution (1 in 20) is between 6-8 and its pKa value is 3.8. Its chemical structure is: **Empirical formula:** $C_7H_{15}NO_3$ **Molecular weight:** 161.20. **Clinical pharmacology:** CARNITOR® (Levocarnitine) is a naturally occurring substance required in mammalian energy metabolism. It has been shown to facilitate long-chain fatty acid entry into cellular mitochondria, therefore delivering substrate for oxidation and subsequent energy production. Fatty acids are utilized as an energy substrate in all tissues except the brain. In skeletal and cardiac muscle they serve as major fuel. Primary systemic carnitine deficiency is characterized by low plasma, RBC, and/or tissue levels. It has not been possible to determine which symptoms are due to carnitine deficiency and which are due to the underlying organic acidemia, as symptoms of both abnormalities may be expected to improve with carnitine. The literature reports that carnitine can promote the excretion of excess organic or fatty acids in patients with defects in fatty acid metabolism and/or specific organic acidopathies that bioaccumulate acyl CoA esters. Secondary levocarnitine deficiency can be a consequence of inborn errors of metabolism. CARNITOR® (Levocarnitine) may alleviate the metabolic abnormalities of patients with inborn errors that result in accumulation of toxic organic acids. Conditions for which this effect was demonstrated are: glutaric aciduria II, methyl malonic aciduria, propionic acidemia, and medium chain fatty acyl CoA dehydrogenase deficiency. Autointoxication occurs in these patients due to the accumulations of acyl CoA compounds that disrupt intermediary metabolism. The subsequent hydrolysis of the acyl CoA compound to its free acid results in acidosis that can be life threatening. Levocarnitine clears the acyl CoA compound by formation of acyl carnitine which is quickly excreted. Levocarnitine deficiency is defined biochemically as abnormally low plasma levels of free carnitine, less than 20 µmol/L at one week post term and may be associated with low tissue and/or urine levels. Further, this condition may be associated with a ratio of plasma ester/free levocarnitine levels greater than 0.4 or abnormally elevated levels of esterified levocarnitine in the urine. In premature infants and newborns, secondary deficiency is defined as plasma free levocarnitine levels below age related normal levels. **Indications and usage:** For the acute and chronic treatment of patients with an inborn error of metabolism that results in secondary carnitine deficiency. **Contraindications:** None known. **Warnings:** None. **Precautions:** Carcinogenesis, mutagenesis, impairment of fertility - Mutagenicity tests performed in *Salmonella typhimurium*, *Saccharomyces cerevisiae*, and *Schizosaccharomyces pombe* indicate that levocarnitine is not mutagenic. No long-term animal studies have been performed to evaluate the carcinogenic potential of levocarnitine. It should be consumed slowly and doses should be spaced evenly throughout the day to maximize tolerance. **Pregnancy:** Pregnancy Category B - Reproductive studies have been performed in rats and rabbits at doses up to 3.8 times the human dose on the basis of surface area and have revealed no evidence of impaired fertility or harm to the fetus due to CARNITOR® (Levocarnitine). There are, however, no adequate and well controlled studies in pregnant women. Because animal reproduction studies are not always predictive of human response, this drug should be used during pregnancy only if clearly needed. **Nursing mothers:** It is not known whether this drug is excreted in human milk. Because many drugs are excreted in human milk, a decision should be made whether to discontinue nursing or to discontinue the drug, taking into account the importance of the drug to the mother. **Pediatric use:** See Dosage and administration. **Adverse reactions:** Transient nausea and vomiting have been observed. Less frequent adverse reactions are body odor, nausea, and gastritis. An incidence for these reactions is difficult to estimate due to the confounding effects of the underlying pathology. Seizures have been reported to occur in patients with or without pre-existing seizure activity receiving either oral or intravenous levocarnitine. In patients with pre-existing seizure activity, an increase in seizure frequency and/or severity has been reported. **Overdosage:** There have been no reports of toxicity from levocarnitine overdosage. The oral LD50 of levocarnitine in mice is 19.2 g/kg. Large doses of levocarnitine may cause diarrhea. **Dosage and administration:** CARNITOR® (Levocarnitine) Injection is administered intravenously. The recommended dose is 50 mg/kg given as a slow 2-3 minute bolus injection or by infusion. Often a loading dose is given in patients with severe metabolic crisis followed by an equivalent dose over the following 24 hours. It should be administered q3h or q4h, and never less than q6h either by infusion or by intravenous injection. All subsequent daily doses are recommended to be in the range of 50 mg/kg or as therapy may require. The highest dose administered has been 300 mg/kg. It is recommended that a plasma carnitine level be obtained prior to beginning this parenteral therapy. Weekly and monthly monitoring is recommended as well. This monitoring should include blood chemistries, vital signs, plasma carnitine concentrations (the plasma free carnitine level should be between 35 and 60 micromoles/liter) and overall clinical condition. 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COVER: Spring and the great outdoors beckons Abigail Rosemary Branson, 17 months—and she's there! Abigail (now 2), who has spina bifida, learned to walk solo with her walker a week after her mom, Susan, snapped this photo. Abigail, her three brothers and sister, and her parents, live in Jackson, MS, where her mom is president of the Spina Bifida Association of Mississippi. Thanks to the Bransons for sharing this photo!

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Parenting your child or young adult with a disability or special healthcare needs
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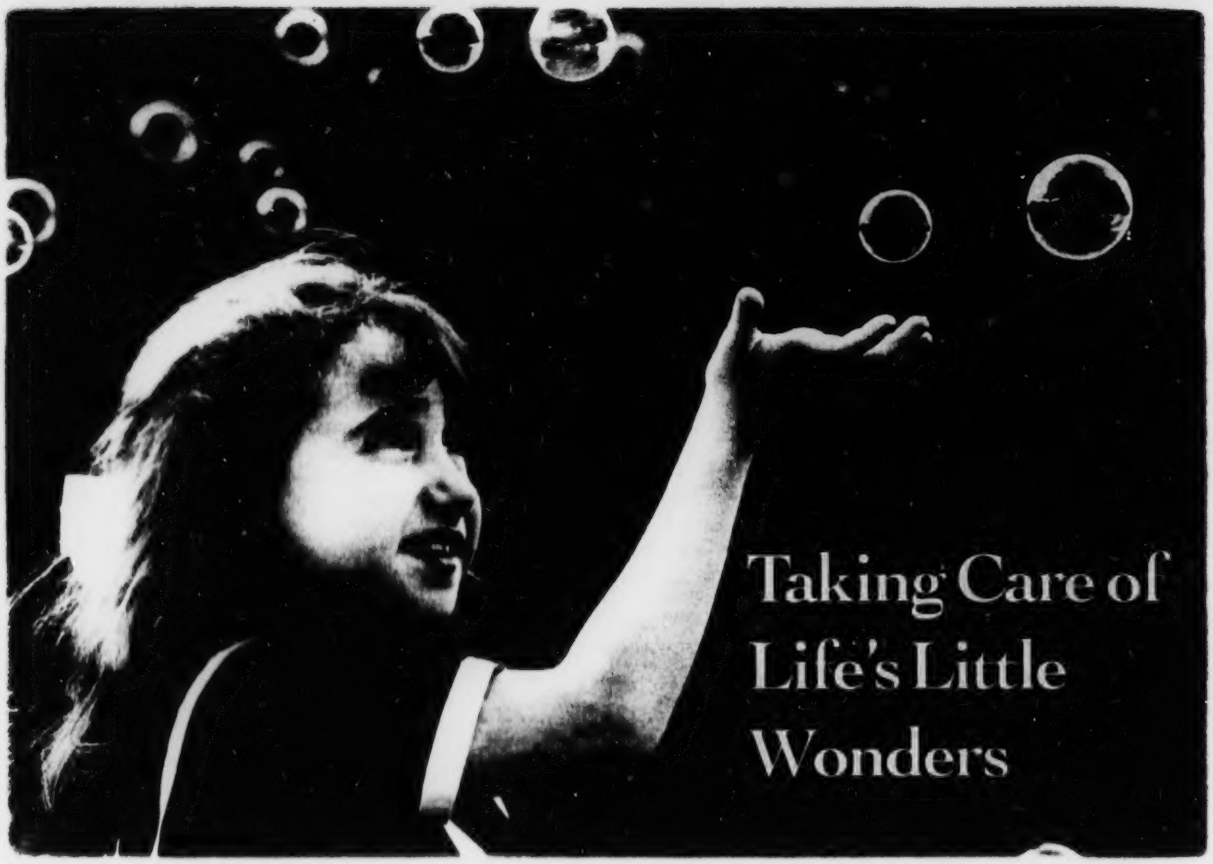
For subscription and advertising information, see page 74



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Circle #26

EDITOR'S DESK

Medical Research Update

In the new millennium, we can expect rapid advances in research into the problems of all people with disabilities and healthcare in general. This month's issue takes a look at what's new under the sun. We also introduce our Medical Research Update column, which will regularly report on medical research relevant to families who have a member with a disability. We welcome the input and contributions to this column from organizations dedicated to particular disabilities.

We are close to describing the total DNA structure—the genetic code that dictates the host of tiny details that makes each one of us who we are. In "The Human Genome Project and the Medicine of the Future," Karin Jegalian, PhD, and Leslie Biesecker, MD, both of the National Institutes of Health, provide an update on the project and what it will mean to all of us.

We have assumed for a long time that this knowledge would lead to therapies which would directly attack problems in the genetic structures that cause so many disorders. However, in the past weeks, great doubt has been cast on the "successful" gene therapy reports we have read in the past several years. The National Institutes of Health has called a halt to the work at The University of Pennsylvania Medical School.

Newspapers have contained articles on the deaths and serious failures in gene therapy that had not been reported. On February 2, 2000, a Senate subcommittee on health began a week of hearings on gene therapy they hoped would contribute to guidelines that would allow the research to continue in a safe, productive fashion. In this issue, Abbey Meyers, executive director of The National Organization on Rare Diseases and a member of a NIH oversight committee, provides a unique overview of the current state of gene therapy research, as well as its problems and prospects.

In debates about "publish or perish" as a basis for tenure at universities, the critical role of research there has been obscured. The current dilemma in gene therapy can be understood by contrasting the role of a university with the role of a private company. When research is done in a university setting, the guiding philosophy has always been to share publicly all information with everyone. In contrast, research sponsored by a private company is guided by the need for privacy to preserve the rights to patenting products. Finding a balance between these two contrasting philosophies has never been more urgent.

Also in this issue

We have included a reprint of the Executive Summary of Defining Medical Necessity, a report developed with the support of the National Policy Center for Children with Special Health Care Needs and the Joseph P. Kennedy, Jr. Foundation. Insurers use this definition of medical necessity to govern whether they will support medical treatments or purchases of adaptive equipment. In upcoming issues we will discuss the problems families often confront when they are denied services and possible solutions. Information on how to obtain the entire report, which is free of charge, is included with the article.

Dr. John Botti, past president of the National Perinatal Association (NPA), describes the role the perinatologist plays in caring for women who are at high risk for having a child with a disability. This article begins a series in which the NPA will introduce us to the various specialists involved in helping promote the growth and development of children with disabilities. The aim of the NPA and these articles is to make families more active and effective participants in the care of their children.

We continue the interview with Aileen and John Crowley, our Hall of Fame parents. In this issue, they describe their management of their health insurance with an example of an arrangement that provided their children with better nursing care and also saved the insurance company money. They also summarize their experience with practical advice for all parents. We hope to revisit them in our ongoing search for important parental wisdom.

This month, CAST, the Center for Applied Technology, based in Peabody, Massachusetts, discusses their Universal Design for Learning™. The concept, which the group pioneered, uses technology to allow students of all learning abilities to access the ordinary curriculum. With judicious use of computers, access can be gained without losing the challenge necessary to stimulate learning.

Our Role Model for March is Jay Leeuwenburg, an offensive lineman with the National Football League's Cincinnati Bengals. At twelve he was diagnosed with juvenile diabetes, a lifelong chronic illness. His family's approach to informing his classmates and teachers about the problems he was facing and their ability to help him learn the importance of taking his daily medication is a lesson for all families whose children have chronic health problems. His ongoing work with the Juvenile Diabetes Foundation is a tribute to him as well as his family.

Hold this date: May 28-May 31, 2000

We are pleased to announce that EP will collaborate with the prestigious MassGeneral Hospital for Children to present a conference and exhibit, Humanizing Health Care for Children and Families: The Art of the Relationship. This promises to be an informative and exciting endeavor, and we hope you will be a part of it. Look for more information in upcoming issues.

Maxwell J Schleifer

Maxwell J. Schleifer, PhD
Editor-in-Chief

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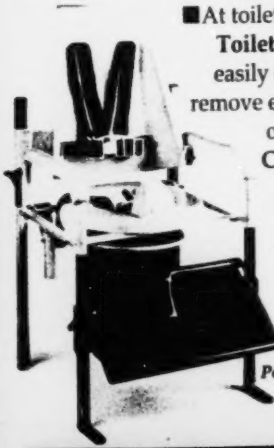

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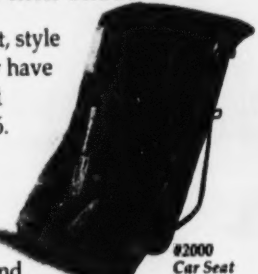

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Circle #29

SEARCH

Aggressive behavior

My 12-year-old daughter was diagnosed with hypomelanosis of Ito (a rare disorder characterized by an unusual lack of skin color affecting many areas of the body and associated with other symptoms, such as mental retardation, seizuresvisual and ocular defects, overgrowth of brain tissue, and/or a small head) at the age of 2 years. She also has a seizure disorder, moderate cognitive delays, and many behaviors that are typical of attention deficit-hyperactivity disorder (ADHD). The most difficult part of her disability, however, is that she swats at and hits others, especially children who are smaller than she. This happens if she feels threatened or anxious, e.g., if a small child suddenly comes too close. This limits her opportunities for inclusion in school and recreational activities and makes it difficult to find respite care. We have tried medications for behavioral disorders such as ADHD (Ritalin® and Paxil®), but the behavior has persisted. As my daughter gets older and larger, she encounters less understanding and tolerance from others. I am looking for ideas on other medications and treatment.

J.B., via the EP Web site

How to keep diapers in place

My 5-year-old daughter has spina bifida and has no feeling from the waist down. A vesicostomy (a surgically created opening below the navel) was performed so that her urine currently drains into her diaper and a surgical pad. When she moves around, her diapers pull down, and her pants and shirt get wet. I would appreciate any ideas on ways to keep the diaper pulled up so that she can stay dry.

C.S., via the EP Web site

Dealing with frustration

My 7-year-old daughter used to walk independently and could feed and dress herself. She had a stroke i September and lost most of he functional vision. We are no arranging testing to determine th extent of the stroke. Our greatest problem at this point is her mood. She does not really communicate, and she gets frustrated very easily. Whenever she is faced with something difficult, she has a temper tantrum. It is getting increasingly difficult to handle her. I would appreciate any ideas on dealing with her frustration and temper tantrums.

J.M., via the EP Web site

Swing needed

My 8-year-old son has Angelman syndrome. He has outgrown his baby-toddler swing, and I would like to find one that fits him. A regular swing with a back on it or a net swing would be great. Does anyone know of any companies that offer this kind of equipment?

M.V., via the EP Web site

Search and Respond is an opportunity for our readers to exchange information about their practical experiences in meeting the everyday challenges of life with a child or adolescent who has a disability. We also expect parents to consult appropriate professionals.

Please indicate whether the letter is a Search or a Respond. If it is a Respond, be sure to note in which issue the original Search letter appeared. All responses are forwarded to the writers of the Search letters; some are published. Published letters may be edited for purposes of space and clarity. Please remember to include a phone number in the event that more information is required.

Write or fax: Search or Respond, *EXCEPTIONAL PARENT*, 555 Kinderkamack Rd., Oradell, NJ 07649-1517, (201) 634-6570 or visit Search and Respond on our Web Site: http://www.eparent.com. For information about specific disabilities, contact: the National Organization for Rare Disorders (NORD), 100 Rt. 37, PO Box 8923, New Fairfield, CT 06812; (800) 999-6673; (203) 746-6518 (http://www.NORD-RDB.com/~orphan). Also, see "National Resources for Specific Disabilities and Conditions" in *EXCEPTIONAL PARENT's* 1999 Resource Guide (January 1999).

The National Parent-to-Parent Support and Information Service (NPPSIS) is a not-for-profit service that keeps track of children with diagnosed and undiagnosed disabilities whose parents are looking for a match. Parents are matched with a "veteran parent," with an older child who has a similar condition and is willing to provide guidance and support. Contact: NPPSIS, P.O. Box 907, Blue Ridge, GA 30513; (800) 651-1151 (V/TTY) or (828) 494-5415; (828) 494-5414 (fax); E-mail: nppsis@elijay.com; Web site: http://www.nppsis.org.

EXCEPTIONAL PARENT

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- *To reach out to mothers and fathers of children and young adults who have disabilities and special healthcare needs.*
- *To empower parents and professionals by providing practical information and emotional support.*
- *To appreciate that parents are the most important experts in the lives of their children.*
- *To energize parents and professionals.*
- *To share ideas and experiences so parents, professionals, people who have disabilities, and other advocates can learn from one another and better collaborate to serve all children and families.*

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HOWARD SHANE, Ph.D., Director, Communications Enhancement Center, Children's Hospital, Boston, MA
HELEN TAGER-FLUSBERG, PH.D, Senior Scientist, Eunice Kennedy Shriver Ctr for Mental Retardation and Developmental Disabilities, Waltham, MA
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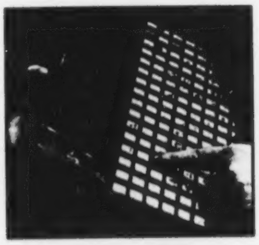

Probable metabolic disorder

H.H., December 1999 (via the EP Web site), has a son who is undiagnosed. He has feeding difficulties, a seizure disorder, developmental delay, and a high level of lactic acid in the blood. She requested information on further testing to help determine a diagnosis, and also wanted ideas on seizure medications that would not make the mitochondrial disorder worse.

Your situation reminds me of my own 11-month-old boy. He spent his first 3 weeks of life in the hospital because of seizures, lethargy, and failure to suck. All test results were normal except the EEG, and he had a carnitine deficiency, for which he received treatment. The doctors thought that the low carnitine levels might be because I am a vegetarian. After a month on treatment, his carnitine levels were high and the treatment was stopped. Now his carnitine levels are low again.

His seizures are now controlled with medication. He has cortical vision problems, reflux, and constipation. His muscle tone is very low and his motor development is delayed. He can only sit for a few seconds at a time and has not developed any equilibrium reactions. The muscles in his arms are very tight. We see a geneticist but would like to get a second opinion. Our next step is muscle biopsy, as we are desperate for answers.

Cheryl, via e-mail

Autism and toileting issues

D.F., December 1999 (via the EP Web site), has a son who has autism and severe cognitive deficits. He seems to have a compulsion to touch his feces and rectum. She requested ideas for behavioral intervention.

Our 7-year-old son has multiple disabilities, including cerebral palsy, mental retardation, cortical blindness, seizure disorder, and hydrocephal (he has a shunt). He also has ma behavioral characteristics that ar typical of autism.

We discussed the problem of feces smearing with behavioral experts who agreed that the most effective method is to make it impossible to get to the feces.

We use bib overalls, one-piece pajamas, and have even made a "onesie" for larger boys. This is somewhat of a nuisance, because our son has a G-tube and this makes feeding difficult. It seems, however, that if we can break this cycle of behavior for a couple of months, he forgets it for a while.

The behaviorists could not explain why someone would want to smear feces, but suggested that it may have to do with their texture and smell. They suggested offering him gooey materials, such as silly putty or finger paints, for play.

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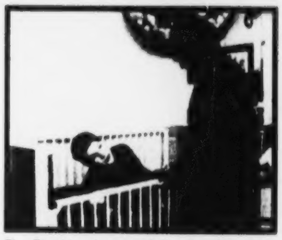

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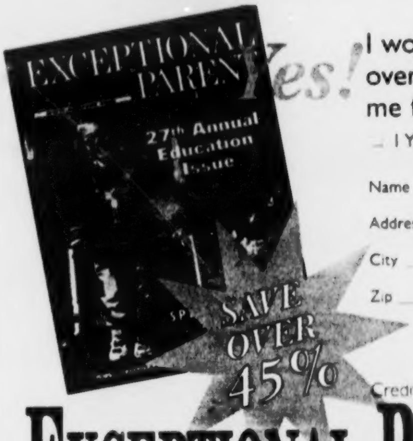

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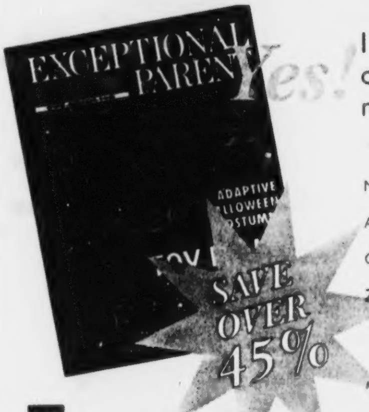

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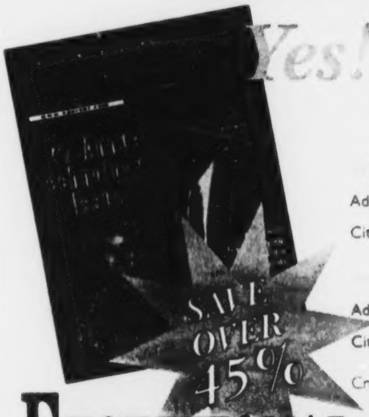

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Circle #48

GENE THERAPY

Balancing the Promise With the Reality

by Abbey S. Meyers

On September 17, 1999, four days after receiving a gene therapy infusion at the University of Pennsylvania, a young man from Arizona who had a genetic disease known as Ornithine Transcarbamylase Deficiency (OTC) died. His death—the first that could be directly linked to gene therapy—electrified the scientific community and triggered a national debate that will have a powerful impact on the future of gene therapy experiments and how they are approved and monitored. These are profound and important questions left unanswered, but for Jesse Gelsinger, the 18-year-old who died, and perhaps for others, it is a debate that came too late.

WHAT IS GENE THERAPY?

The concept of gene therapy was born when scientists theorized that if they could replace faulty genes with good ones, they would be able to cure hereditary disorders. The problem was how to get good genes into cells. Scientists knew that cells were masterful at protecting themselves, and that it would be important to insert new genes in a way that left them intact and able to function. They realized that one of the few entities that could enter a cell and reside inside for a long period of time was a virus. Thus, they launched a series of animal experiments using a genetically modified virus (called a "vector") that would carry a desirable gene, much like a passenger in a taxi, and drop it off in the targeted cell. To assure that the virus would not multiply and cause disease in the recipient, they modified it so it could not replicate after it delivered the gene.

During the1980s, scientists working in this field realized that if gene transfer worked in humans, it would raise profound moral and ethical questions. Gene therapy, they theorized, could change the human race if there were no ethical parameters and no regulatory boundaries that scientists would have to obey. Moreover, designing new viruses would trigger environmental questions that could potentially pose new risks to humanity. In light of all this, they met together and proposed that the government should create an oversight structure called the Human Gene Therapy Subcommittee of the Recombinant DNA Advisory Committee (which is known as the "RAC"), to review pending gene therapy experiments and monitor the progress of the technology. These scientists felt that if gene therapy experiments were reviewed and discussed in open meetings by ethicists, scientists, and members of the public, it would build public trust and reduce fear of genetic engineering. The major threat to the future of gene therapy, they surmised, would be public suspicion that experiments conducted behind closed doors might lead to the creation of genetically engineered humans, potentially turning frightening science fiction into reality.

GOVERNMENT REGULATION

As a result of these recommendations, the National Institutes of Health (NIH) created the Human Gene Therapy Subcommittee, which developed a list of rules that scientists would have to abide by before, during, and after they transferred new genes into humans. These rules are parts of the "NIH Guidelines for Research Involving Recombinant DNA Molecules," and they are known as the "Points to Consider." The rules must be obeyed by all scientists who receive federal funds, as well as by private companies when treatment of patients is provided at a hospital that receives federal funds, such as Medicare or Medicaid. After the RAC would approve a protocol, scientists would have to obtain FDA approval before an experiment involving humans could begin.

EARLY TRIALS

Even though gene therapy was conceived as a technology that would treat or cure genetic diseases, within a short period of time, the great majority of experiments focused only on cancer. This was primarily because gene therapy experiments are very expensive, and the NIH was not generous in its funding to academic investigators who wanted to pursue gene therapy. The federal government funded only three vector manufacturing facilities, so the private sector stepped in, and pharmaceutical companies sponsored trials at an increasing rate each year. Pharmaceutical companies know that genetic diseases are generally rare, and there would be much bigger and more lucrative markets for products to treat common diseases such as cancer or heart disease. As a result, the field turned away from the genetic diseases it was most likely to cure, and moved toward diseases for which it was easiest to get funding. By September, 1999, the RAC had approved 295 gene therapy protocols, 206 of which were for cancer.

The first human trial of gene therapy was for Severe Combined Immune Deficiency (SCID), more commonly known as the "Bubble Boy Disease" because of the young Texas boy who lived for years in a plastic bubble that protected him from germs. However, just before the SCID experiment was launched, a pharmaceutical company had developed an "orphan drug" that replaced the missing enzyme (adenosine deaminase) in children with this disease. Thus, this type of SCID was no longer an untreatable and deadly genetic disorder, so the RAC required the investigators to continue giving the children the drug until they could prove that the transferred gene made injections of the enzyme unnecessary.

...A NATIONAL DEBATE THAT WILL HAVE A POWERFUL IMPACT ON THE FUTURE OF GENE THERAPY EXPERIMENTS AND HOW THEY ARE APPROVED AND MONITORED.

This initial gene transfer protocol received extraordinary publicity, and even today the public believes it was successful. In terms of transferring the needed gene, it was indeed successful; but, the fact is, the new genes were unable to manufacture enough of the enzyme to make any difference in the children. Even now, the children with SCID who have received gene therapy treatments still rely on the injectable enzyme. However, the positive news about this experiment became a pattern that persisted in the news media: report the good news and ignore the negative facts.

In time, the Gene Therapy Subcommittee was merged into the RAC, and even today the RAC continues to review gene therapy protocols in a public forum every three months. Every six months, the RAC is given a report on the progress of all approved protocols. These reports are supposed to disclose how many patients have been enrolled in each, any adverse events that have occurred, and the causes of any deaths. However, over time, as the RAC would review the progress reports, its members noticed that few adverse events were being reported, and several critical questions were not being answered.

For one thing, probably because the great majority of experiments have been on terminal cancer patients, there have been many deaths. However, there is no way to tell for certain whether the deaths are in any way related to the gene transfers. This is because one would reasonably expect that terminal cancer patients would die of cancer if the gene transfer did not help them. Also, to date, gene therapy has not been therapeutic, no one has been cured, perhaps because of the efficiency of the human immune system. Since most experiments have used vectors called "adenoviruses"—viruses that cause common colds in humans—an immune response would naturally be triggered to destroy the virus and its passenger, the new gene.

Furthermore, the NIH Points to Consider require that, in the event of a patient's death (for any reason, whether related to the gene therapy or not), an autopsy will be requested to determine whether the vector or transferred gene played any role in the death, and whether the new gene reached the patient's reproductive organs (which might indicate unintended consequences for future generations). These are important questions. But today, after approximately 3,000 humans have participated in gene transfer experiments, only a handful of autopsies have been done.

The Push Toward Deregulation

During the mid 1990s, the pharmaceutical industry complained that too much time was being wasted in the RAC review process. So the NIH was completed to change the rules. Experiments that were not unique, and those that used vectors that had already been utilized in numerous other experiments, would no longer have to be reviewed by the RAC in a public forum. They would go directly to the FDA. Only novel protocols using new vectors, or experiments on new diseases that were not previously the subject of gene therapy investigations, would continue to be reviewed by the RAC.

Once a protocol goes to the FDA, it becomes enshrouded in protective secrecy because the FDA considers all information a "trade secret" unless the sponsor agrees to release data. Since most gene therapy protocols were simply dupli-

continued on page 22

No one has been cured, perhaps because of the efficiency of the human immune system, since most experiments have used vectors called "adenoviruses"

continued from page 21

cations of experiments already under way, there was no protest against this change of the rules. Although many people asked why there was a need to rush experiments that had shown no therapeutic benefit, there was no formal objection registered to trigger a public dialogue about this change in NIH rules.

Biotechnology companies complained that the RAC was unduly restrictive. The industry said it was regulated by the FDA, and therefore it was improper for the NIH to impose its rules on private companies. To everyone's surprise, in the spring of 1995, the NIH director, Dr. Harold Varmus, announced that he was going to dissolve the RAC. This meant that there would be no further public discussion and no public input into gene therapy investigations. If a scientist decided to transfer genes to make a person taller, or smarter, or change his hair or skin color, there would be no opportunity for ethical objections. Investigators could stop pursuing cures for diseases and redirect their studies to cosmetic gene therapy, which might ultimately threaten the diversity of the human race through engineering of "designer children."

Doctor Varmus' announcement provoked an outcry, not only in the United States, but around the world. Other countries admired what the RAC was doing, and they had created their own RAC-type regulatory bodies to monitor gene therapy experiments. When members of Congress protested, Dr. Varmus changed his mind. One year later he announced that he would reduce the RAC from 25 members to 15, and no longer allow them to vote for or against approval of protocols. However, the RAC would continue to exist. The weakened Committee's only remaining tool was to serve as a pulpit against scientific excesses.

Between December 1995 and December 1996, there were no RAC meetings while a political battle raged among the NIH, Congress, and the public. One of the last protocols that the RAC approved, before its meetings were halted in 1995, was for a genetic disease called Ornithine Transcarbamylase Deficiency (OTC), which is a rare urea-cycle disorder. The urea-cycle disorders are characterized by enzyme deficiencies or enzyme abnormalities that can cause excessive elevations of ammonia in affected individuals. Children with this disorder go into a coma and they usually die. However, an orphan drug is now available to treat many of the urea-cycle disorders, including OTC. If an individual with a mild genetic defect for OTC takes the medicine and follows a strict diet, he or she may live a nearly normal life.

The scientists who proposed the study wanted to inject the vector (an adenovirus) into the artery leading to the liver of individuals with OTC deficiency, and they wanted to do the experiment on children. The RAC disagreed. Because OTC Deficiency was a treatable disease, the RAC told the investigators they had to do the experiment on adults (over 18 years of age), and they could not put the vector into the liver because of concern that it might cause a severe reaction. Instead, the RAC told the investigators to put the vector into a vein via intravenous infusion. The scientists agreed to make these changes, and the newly designed protocol was approved.

CRISIS TRIGGERS REFORM

Following Jesse Gelsinger's death, an autopsy confirmed that the adenovirus had triggered an overwhelming attack by his immune system which destroyed his liver and other organs. Within days, the Washington Post reported that at least six more deaths had occurred in other gene therapy experiments that had not been reported to the RAC. Additionally, the FDA was aware of several deaths and severe adverse events from gene therapy that were not reported to the RAC. The sponsors of those studies claimed these were "trade secrets," and refused to allow the FDA to release the information. Moreover, even though the investigators on the OTC experiment were required to report any changes to the protocol after the RAC reviewed it, they did not inform the RAC that they had decided to infuse the vector into the liver despite the RAC's instructions not to do so.

The tragic death of Jesse Gelsinger has raised many profound questions that will haunt the field of gene therapy for years to come. Why haven't investigators and companies obeyed the RAC's reporting rules? Why have they kept important information secret? Why have only the positive results been released to the news media? Under what circumstances can a company ethically claim that a death is a "trade secret?" With the potential to alter the human race, who's purpose is served if this research is done behind closed doors? And, most of all, why have two critical government agencies—the FDA and the NIH—competed instead of cooperated when lives were at stake?

The industry may have felt that it was important to claim success prematurely because this is the only way to raise investment capital. But, by withholding the truth, they were not being honest to their stockholders, or to the brave patients who volunteered to participate in clinical trials. Many patients were led to believe that, while gene therapy technology does not work very efficiently, at least it is safe. If adverse events were not reported to the RAC, as required patients who considered participating in the trials had no way to learn the truth. For example, in the OTC experiment, three patients who had participated before Jesse Gelsinger had abnormal liver enzyme tests after the vector was infused, and several monkeys had died before the vector was given to humans. However, these facts were hidden from potential participants, and not reported to the RAC until after Gelsinger died.

A major aim of the RAC is to share information so that mistakes can be avoided by other gene therapy scientists around the world. In that way, precious resources will not be wasted duplicating experiments that have already been done. It is not yet clear whether Dr. Varmus' attempt to dissolve the RAC in 1995 encouraged investigators to ignore the RAC's rules and hide the truth in the field of gene therapy. Why was the private sector allowed to dominate the field when the NIH knew that much more basic research was needed to make gene therapy safer and more effective?

The soul searching that has occurred since the Gelsinger death marks a turning point in gene therapy research. It has made the value of the RAC more obvious and the importance of public participation in research dialogue painfully clear. History has shown that scientists will sometimes go to

continued on page 24

> ONCE A PROTOCOL GOES TO THE FDA, IT BECOMES ENSHROUDED IN PROTECTIVE SECRECY BECAUSE THE FDA CONSIDERS ALL INFORMATION A "TRADE SECRET" UNLESS THE SPONSOR AGREES TO RELEASE DATA.

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Circle #55

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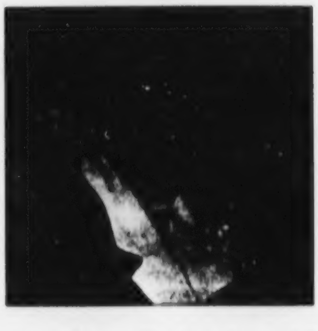
extraordinary lengths to test their hypotheses, sometimes overlooking patient protections. As a society, we cannot allow gene therapy scientists to perform experiments in secret that could affect future generations of unborn children, just because they want to prove a point.

Other troubling issues persist, however. Some see the day when "designer children" become a reality, and parents will be able to choose their babies' eye and hair color, IQ, height, and weight. While most people feel this concept is distasteful, some are eager and willing to pay for the privilege. In a country that does not even guarantee every citizen the right to health insurance, one can only imagine the widening medical gap between rich and poor if we could buy access to a technology that would change our genes. For example, who will decide which skin color is preferable? Will those who do not have the proper skin color suffer as outcasts? Will diversity eventually become a crime?

Ultimately, it is the way this gene therapy controversy has affected patients that is most disturbing. During the past decade, families with hereditary diseases felt it would soon be possible to replace faulty genes with good ones, so that future generations could be born disease-free. Now they know this is not true, and the dream is not yet a reality. It may take another decade or more before safe and effective gene therapy can be developed with new vectors that will not arouse the immune system. The best thing that can come out of the tragic death of Jesse Gelsinger is that patients who volunteer for clinical trials will be treated honestly, so they understand the risks. Scientists and corporations will be more sensitive to the public's need to know what they are doing, and finally, families will not base important medical decisions on news reports that were aimed at Wall Street and only accidentally filtered down to Main Street.

Someday gene therapy will accomplish all the miraculous medical achievements it was conceived to do. But when this happens, we will learn about it from peer-reviewed medical journals, not the nightly news. And when gene therapy is finally deemed safe and effective, the challenge will be to confine its use to the treatment and cure of diseases, thus preventing re-engineering of the human race. **EP**



Abbey S. Meyers is the founder and president of the National Organization for Rare Disorders (NORD). Ms. Meyers was a member of the NIH Gene Therapy Subcommittee from 1989 to 1992, and the Recombinant DNA Advisory Committee (RAC) from 1993 to 1996. She served as the consumer representative on these committees. She has three children with a genetic disease, and five grandchildren who are "at risk" of inheriting it.

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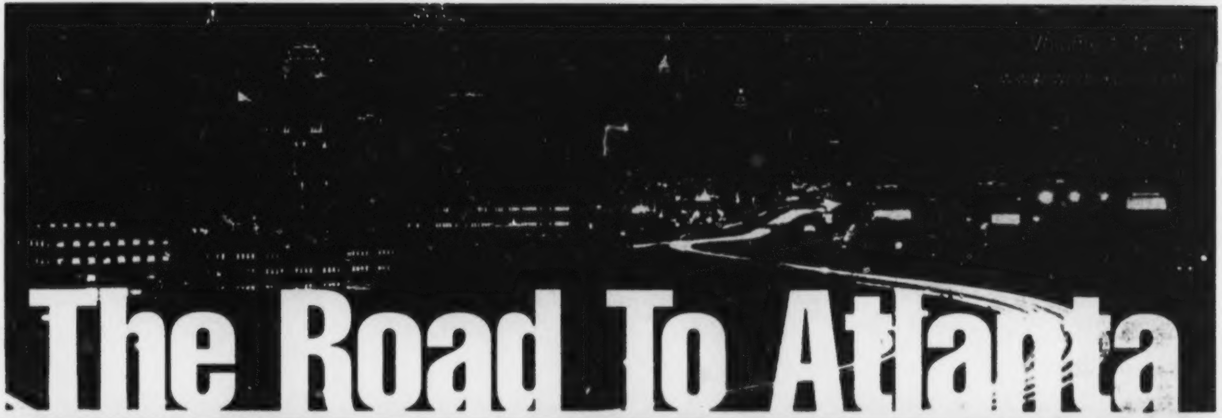

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Village, Assistive Technology, Inc., Baby Jogger, Children's Healthcare of Atlanta, Children's Hospital, Columbia Medical Systems, Guldmann, Keybowl, Kimberly-Clark, Lifestand, MetLife Financial Services, New Mobility Magazine, (Pediatric Neurotransmitter Disease), Pride Mobility Products, R. D. Equipment, Sigma-Tau Pharmaceuticals, Sports and United States Disabled Athletes Fund. And the list is growing. Check next issue for more!

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Paralympic and National Level Athletes to Demonstrate Their Abilities at WCD

The U.S. Disabled Athletes Fund (USDAF), a national non-profit organization, will present top athletes in sports demonstrations at the World Congress & Exposition on Disabilities, November 10-12, 2000 at the Georgia International Convention Center in Atlanta. Demonstrations will be held every day of the show and where appropriate, spectators—both able-bodied and disabled—will be involved. Sportsbeing demonstrated include: Wheelchair Track, Wheelchair Rugby, Wheelchair Tennis, Wheelchair Basketball, Wheelchair Fencing and Track for the Visually Impaired, as well as Orthopedic and Prosthetic Track and Field. Athletes expected to appear include numerous Paralympic medallists, members of the Atlanta Rolling Hawks and Rolling Thunder.

As the successor organization to the Atlanta Paralympic Games, the USDAF was developed as a non-profit organization to address the needs of children and adults with disabilities to have the opportunities to participate in sports. The mission of the USDAF is to advance the disability sports movement in the United States to improve the quality of life and economic self-sufficiency of Americans with physical disabilities. In working toward this mission, USDAF developed BlazeSports, a state-funded model program to deliver sports for persons with disabilities from beginning levels through to training and competition opportunities for elite athletes. The focus of USDAF is two-fold: 1. To serve as a catalyst for the development of organized sports programs for children and adults with physical disabilities; and 2. To foster the expansion of these programs into local communities so that children and adults with physical disabilities have the same opportunity to experience the benefits of sports and recreation as their able-bodied peers.

At the grassroots level, the BlazeSports program offers five Paralympic sports throughout Georgia through Parks & Recreation Departments. The schedule has not yet been finalized but will be available soon on www.wcdexpo.com. Those interested in contacting USDAF may do so at http://education.gsu.edu/blazenet or blazesports@mindspring.com. or by telephone at 770850-8199, fax 770 850 8179.

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THE HUMAN GENOME PROJECT

and the Medicine of the Future

by Karin Jegalian, PhD and Leslie Biesecker, MD

The most ambitious biological science project ever conceived is under way and will profoundly affect how medicine is practiced in the next century. This project is the Human Genome Project (HGP), and its goal is to determine the DNA sequence of every gene in the human body. The HGP is fueling rapid discoveries into the genetic basis of a wide range of conditions. By laying bare the human DNA code, scientists are creating a deep understanding of how our bodies work, an understanding that builds from the most basic level of genes.

A thorough understanding of the molecules of life promises to transform science and medicine: from molecules, scientists can better understand cells; from cells, researchers are understanding better how tissues and bodies work. The details are not easy to unravel, but researchers increasingly can trace how molecular alterations translate into physical symptoms. The HGP promises to yield insights about nearly all health problems and, ultimately, yield treatments for many conditions, whether inherited or not. Many, if not all, exceptional children will be affected by these discoveries, and some have already benefited. It is crucial that those affected by the discoveries should understand and appreciate what this project is about and how it will alter the medicine of the future.

THE GENETIC PERSPECTIVE

Genes are not everything, but they are very important. Genes are encoded within DNA, the molecule that transmits traits from parents to children. The genes that we inherit instruct our bodies in the steps necessary to build cells, tissues and organs, and how to break down food and use those breakdown products to build critical molecules to maintain health. Other genes make signaling molecules while still others make molecules that receive and process those signals. How all the components of life come together from a set of genes is like the creation of a symphony from sheet music—the creation of a harmonious whole from nothing more than spots of ink on pages of paper. Like music, the language of genes may appear simple, but in a living creature, the building blocks—or individual genes are woven together with beautiful intricacy to create a complex organism. Decoding the language or code of our genes will allow scientists to

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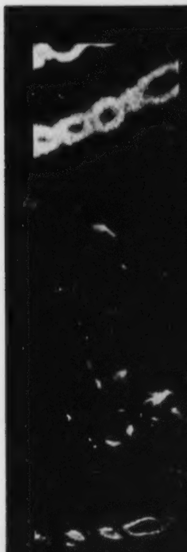

A chromosome test called FISH (fluorescent in situ hybridization) can highlight whether a child suspected of having velocardiofacial syndrome is missing a piece of chromosome 22 to confirm the diagnosis.

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understand in detail the enormously complex set of instructions that shape a human being.

To unravel the mystery of the code, scientists study both normal and abnormal genes. In this way, the importance of each gene can be defined and the consequences of gene dysfunction understood. An understanding of how each gene works can benefit us in many ways. Knowledge about normal and altered genes will assist diagnosis and treatment of a wide range of disorders. The Human Genome Project is the first step toward understanding the function of all of our genes and how those genes affect our health.

GENES AND ACCURATE DIAGNOSIS

Even before the function of a gene is understood, knowing that a particular gene somehow causes a particular disorder can be very useful. The knowledge can be used immediately to help with the problem of accurate diagnosis. Many medical diagnoses lump together ailments that actually represent a group of overlapping, but distinct diseases. For example, cerebral palsy and autism are diagnoses that each include a tangle of conditions that are probably distinct in origins and effects. When a diagnosis includes a mixed set of conditions, a child's diagnosis does not necessarily reveal much about what kind of future that individual child is likely to have, nor how that child should be treated to minimize symptoms. Refined and accurate diagnoses lead to prognoses that are more reliable and allow more informed decisions to be made about care.

HOW KNOWLEDGE OF GENES HELPS TREATMENT

For only a relatively small number of conditions do scientists understand the molecular abnormality at the root of the condition and how that abnormality causes the disorder. The HGP will supply the resources to help reveal the origins of nearly all disorders. The HGP has dramatically increased the rate at which human genes are being discovered. Little more than a decade ago, disease genes could be identified only if scientists already understood the biochemical problem they were facing, a prerequisite that left most disorders as unapproachable mysteries.

Now, scientific journals report the discovery of a new disease gene practically every week. The HGP helps scientists find disease genes based purely on genetic features like genes' positions in DNA, which means the basis of a disease can be discovered without any inkling in advance about the cause. The pace of discovery is accelerating. Ten years ago, the gene for cystic fibrosis was found after an arduous nine-year search. Eight years later, a gene for Parkinson's disease was found in only nine days.

Understanding pathogenesis—or how exactly a disorder arises—can reveal targets for intervention to prevent, mitigate, or reverse health problems. Finding a gene does not always lead to easy answers; for example, the molecular defect responsible for sickle cell anemia has been known since the 1950s, and medications can control some of the symptoms of this ailment. However, no one knows how to cure it. The gene for cystic fibrosis was discovered in 1989; ten years later, no treatments based on the discovery are yet on the market. However, understanding the genetic alteration in cystic fibrosis has fueled energetic attempts to design better drugs. Now, more than a dozen such drugs, based on an understanding of the protein encoded by the cystic fibrosis gene, are in clinical trials.

Sometimes finding a gene yields more immediate benefits. For example, the gene responsible for a form of inherited colon cancer called familial adenomatous polyposis, or FAP, was discovered in 1991. The gene, called APC, is often mutated in cases of sporadic colon cancer as well. But when a mutated APC gene runs in a family, even children and teenagers can be at risk for colon cancer. With the discovery of the gene, genetic testing became possible. In the case of colon cancer, cure rates are very good when tumors are caught and removed early. Genetic testing can reveal who is particularly susceptible and should embark upon a program of regular, close surveillance for colon polyps. Meanwhile, family members who find they do not have genes that put them at risk can confidently forego the screenings.

Genetics is also helping sort congenital heart defects, which affect nearly 1 percent of babies, into distinctive syndromes. One of these is velocardiofacial syndrome (VCF), caused by the absence or malfunction of a gene or group of genes on chromosome 22. Children with this disease often have cleft palate—but not all do—though they have the cardiac defect, which usually affects the aorta where it connects to the heart. A chromosome test called FISH (fluorescent in situ hybridization) can highlight whether a child suspected of having velocardiofacial syndrome is missing a piece of chromosome 22 to confirm the diagnosis. VCF is a good example of how a molecular test improves our understanding of a disorder. In the past, the syndrome was only thought to exist when a person had many manifestations (heart defect, cleft palate, and developmental delay). However, the availability of the molecular FISH test showed scientists that some people, including relatives of people with all the features of VCF, have only an isolated heart defect. This is a case where genetic tests have revealed that an underlying genetic alteration is more widespread than previously believed; not all people with a genetic alteration manifest traditional aspects of each syndrome. The genetic explication of these syndromes now means that children born into families where there is a history of these heart anomalies can be tested for a hidden genetic problem so the problems can be treated earlier. Also, the gene test can be used to diagnose children with unexplained heart anomalies; and if the VCF gene region deletion is the cause of the heart problem, that alerts caregivers to possible subtle developmental problems as well.

GENETIC COUNSELING

Genetic counseling is a process that includes risk assessment, education and psychosocial counseling. A precise understanding of the genetic basis for a health problem can help couples determine the risk that a disease will affect future children. If a disorder in one child apparently occurred by random chance, whether because of a rare new gene alteration in the affected child or because of an alteration during development not caused by genetics, parents can be reassured that the risk of recurrence in future children is small.

Congenital heart defects, for example, undoubtedly result from a combination of conditions, some resulting from alterations in a single gene, some from a group of genes acting together, and probably some non-genetic causes. In many disorders (e.g. congenital heart defect), the currently accepted statistics which represent the risk of recurrence, mix together many different conditions that arose for different reasons. No family wants to be counseled on the basis of a recurrence risk figure that reflects an average of these factors. Rather, they want a recurrence risk that accurately reflects their own situation so they can make family planning decisions that are right for their family.

Similarly, genetic counselors can best help families with their concerns when an accurate and specific diagnosis is available. Nearly all parents want a

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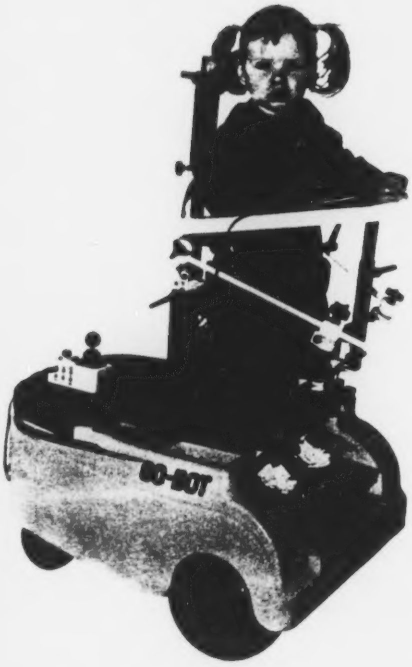

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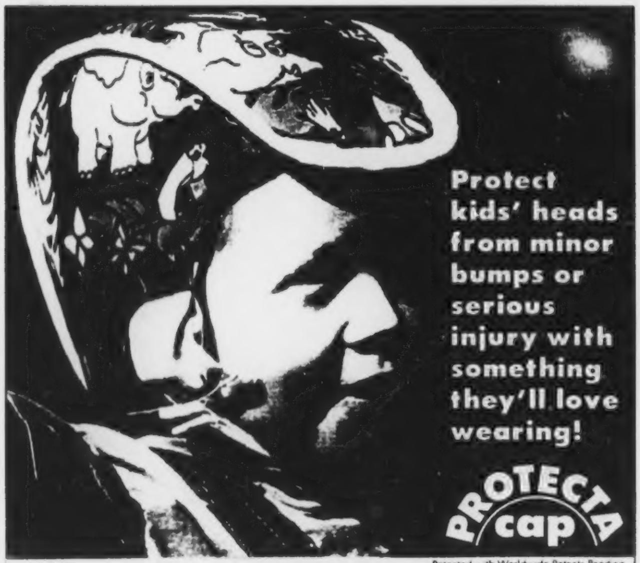
detailed and precise explanation of the cause of their child's problem. Generalizations are much less helpful. The ability to make an accurate diagnosis, provide a valid recurrence risk, and educate families paves the way for focused counseling on the challenges and issues that face the family. When an accurate diagnosis has not been made, much of the counseling process revolves around the issue of diagnostic ambiguity and the resulting frustration. When a specific diagnosis is made, counseling focuses more on coping with what is known about the disorder, dealing with the prognosis, considering reproductive decisions, and other related issues. In this way, genetic counselors can help families cope with the challenges they face and also help them deal with grief and loss.

THE FUTURE

The genetic underpinnings of many more conditions will become apparent in the coming years. The benefits of improved diagnosis and prognosis will spread to many more illnesses. However, achieving direct treatments and cures based on genetic research will take a great deal of scientific effort and time. Understanding in molecular detail the sequence of events that causes physical problems will yield insights on how to intervene in the disease pathway and interrupt it. In time, drugs will be designed to target specific gene products. Some drugs will interact with key proteins—whose place and time of action is understood—and perhaps adjust the level of action of genes.

Molecular genetics and the HGP are not the answer to all of these challenges. The completion of the HGP, expected by 2003, will herald the end of the beginning. That is, we soon will understand what causes most congenital and inherited disorders in human beings. It is a long road to the development of treatments and cures, but we have also traveled a long road from our former ignorance of the causes of these disorders. The HGP is allowing us to move forward with purpose and speed, and that should be a source of hope to all those who have been affected by these conditions. **EP**

Karin Jegalian, PhD, holds a Doctorate in Genetics from Massachusetts Institute of Technology and is a science writer at the NIH's National Human Genome Research Institute (NHGRI). Leslie Biesecker, MD, is an investigator at NHGRI focusing on the molecular and clinical characterization of multiple congenital anomaly syndromes and overgrowth syndromes. He is a board certified pediatrician and medical geneticist.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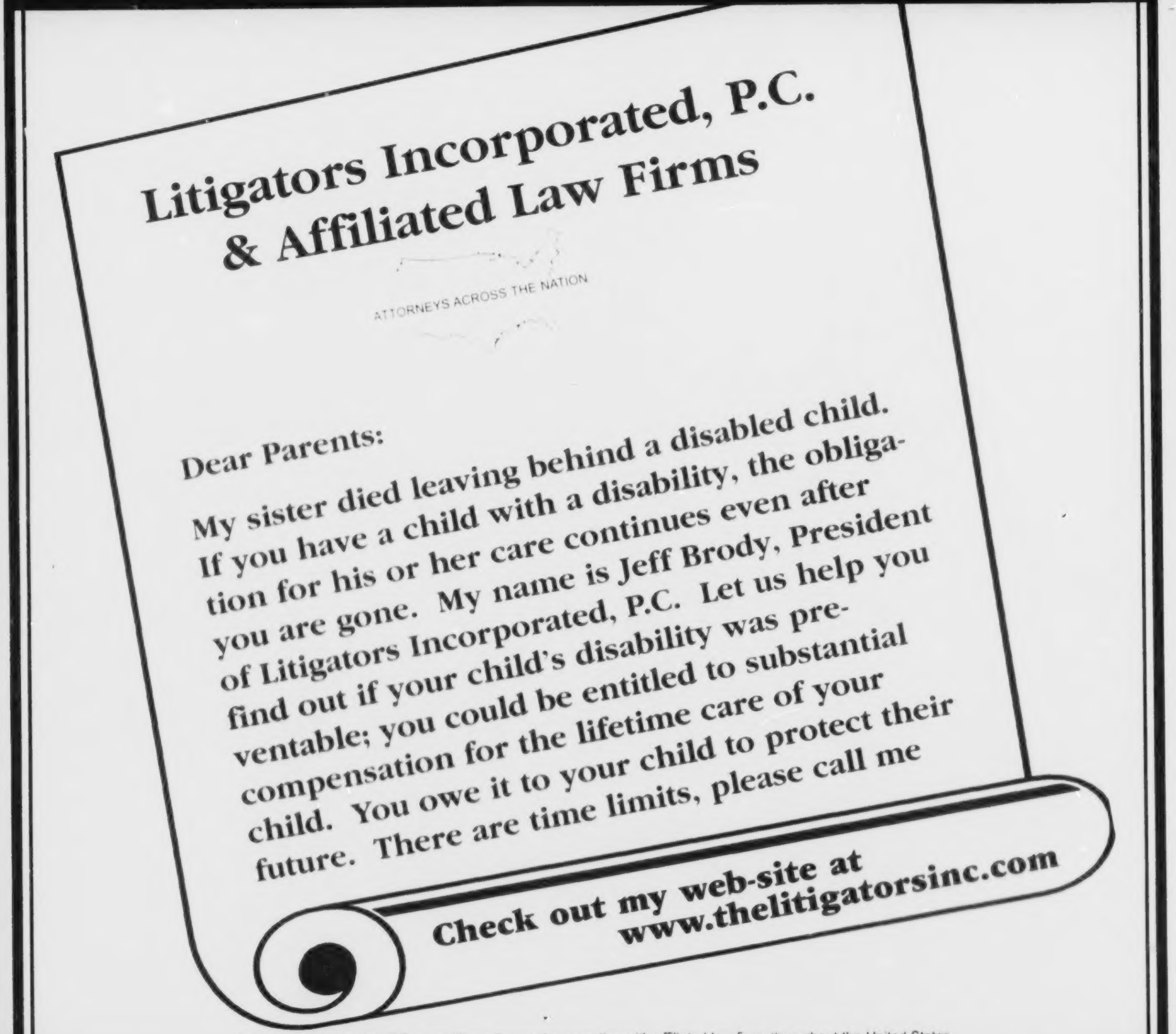

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MEDICAL RESEARCH UPDATE 2000

For many of us, the new millenium holds great promise and opportunity—a chance for a "new beginning." Opening the door to the 21st century has freed our imaginations and bolstered our determination to embrace new aspirations, new discoveries, and new goals. The past year has given life to numerous treatments and research that hold equal promise. Starting this issue, we are going to provide medical research updates on a regular basis.

Compiled by Dave Chamalian

VISUAL IMPAIRMENTS

"Tunnel" Vision Now Possibile

After more than 30 years in development, researchers have developed an artificial vision system called the "Dobelle Eye," which will allow users to achieve some visual function in a "tunnel." The apparatus works as follows: A subminiature television camera and ultrasonic distance sensor are both mounted on a pair of special eyeglasses worn by the user. A miniature computer, mounted to the user's belt and connected to the eyeglases via a cable, processes video and distance signals, then activates a second microcomputer to transmit pulses to electrodes implanted on the surface of the brain's visual cortex. The first implant has been successful, as the user is able to navigate unfamiliar spaces, and is learning to watch TV and use a computer. Research has been done at the Dobelle Insitute in New York City in conjunction with its affiliates on Long Island and in Switzerland. For further information and to see a diagram of the Dobelle Eye, go to the following Web site: http://www.artificialvision.com.

ATTENTION DEFICIT HYPERACTIVITY DISORDER (ADHD)

Treatment and Insomnia

Research is now available that shows a link between the treatment of ADHD and insomnia. The authors of a new study suggest that children with ADHD—who, as a result of their disability, are prone to sleep disorders—who receive stimulants, experience a nearly two-fold rate of insomnia over children who do not receive treatment. The conclusion is that with the prevalence of ADHD (evident in three to five percent of the population) in our society and the common use of stimulant medications to treat it, it is important to monitor the sleeping patterns of children with ADHD before and during treatment to prevent exacerbating sleeping disorders. The Journal of Child and Adolescent Psychopharmacology has recently published this study.

Cautioning Early Diagnosis

An inordinately high number (nearly 60 percent) of small children—as young as 1 year old—are being diagnosed with ADHD and treated with Ritalin®, Prozac®, Zoloft®, and other psychotropic medications. A large percentage of these children have been found to have developed chronic health conditions such as asthma, diabetes, language disorders, and developmental delays. One researcher, MSU pediatrician Marsha Rappley, MD, is cautionary about these seemingly hasty diagnoses. "I don't think you can give a sample diagnosis of ADHD in a child of this age...My hypothesis about this is that the problems of these children are so severe that the physician and parents feel compelled to do something." The study was conducted at the University of Michigan and published in the *Archives of Pediatrics and Adolescent Medicine* .

AUTISM

Benefits of Early Diagnosis

Pauline Filipek, MD, professor of pediatrics and neurology at the University of California—Irvine, suggests in her new study the importance of early diagnosis of autism in children so that treatment can prevent the disease from becoming severely debilitating. According to the study, it is imperative that physicians be trained to spot the early signs of autism and carry out developmental screening of the disease on every well-child visit. "Our research found," says Dr. Filipek, "that children with autism are often not diagnosed until age 5 or 6 but have had symptoms of the disorder for years...We believe one reason for this is that the current practice of brief well-child visits does not provide enough time for primary care practitioners to screen for autism." The study recommends that besides physicians, early-childhood, health, and educational workers be trained to recognize the early signs of autism as well. The study is published in the December 1999 issue of the *Journal of Autism and Developmental Disorders*.

CYSTIC FIBROSIS

Ibuprofen Therapy

Michael W. Konstan, MD, has proved the benefits of a strict, long term ibuprofen regimen. In his extensive clinical study, people with CF (a hereditary pulmonary disease) who have taken high doses of ibuprofen over a four-year period show slower lung deterioration, better preservation of body weight, and fewer hospitalizations than those patients with CF who did not undergo ibuprofen treatment. Results are even better among those who underwent an eight-year, high dose ibuprofen regimen. In either case, Dr. Konstan's team deems it essential that any ibuprofen regimen be adhered to strictly and that it be carefully monitored. Dr. Konstan is the director of the LeRoy Mathews Cystic Fibrosis Center in Cleveland, OH.

Home vs. Hospital Care

Research shows that people with CF who are in the hospital under treatment for pulmonary exacerbation and have exhibited sufficient improvement in lung function benefit by being permitted to go home—provided there is someone to care for them—for the remainder of their IV antibiotics treatment. Individuals receiving treatment feel more comfortable at home, and they have their families around them to provide more balanced, nutritious meals.

Exercise and Nutrition

Clinical researchers stress the importance of regular exercise—including mobility and muscle-strengthening exercises and endurance training—for people with CF, regardless of pulmonary status. An exercise program, say the researchers, complements medical treatment in helping to clear pulmonary secretions. In addition, a diet rich in calories, to energize the muscles during exercise, and adequate fat, to prevent dependence on burning mostly carbohydrates during exercise, is essential. A combination of the proper diet and a regular exercise program will also serve to prevent osteoporosis, or the depletion of bone mass, a common problem found in adults with CF. This research was reported at the 13th Annual North American Cystic Fibrosis Conference.

A Financial Boost for Research and Development

The Bill and Melinda Gates Foundation has awarded a $20 million grant to the Cystic Fibrosis Foundation to be used for accelerating its drug discovery and development program. "One of the missions of [our] Foundation," says Mr. Gates, "is to support organizations that are not only doing something important to improve global health, but are also efficient at what they do." (When the CF Foundation was founded in 1955, most children did not live beyond school age. Today, the median age of survival is 32.) Says Robert J. Beall, PhD, and president and CEO of the CF Foundation, "The potential therapeutics already in the pipleline look very promising...What makes a gift of this magnitude so exciting is that it will allow us to exploit technology that will increase the volume in this pipeline exponentially..."

DOWN SYNDROME

Hearing Loss

Authors of a new study, Daniela Curti Thome, MD, Tanit Ganz Sanchez, MD, Ricardo Ferreira Bento, PhD, Maria Elisabete Bovino Pedalini, Elisa Maria Moreira Carcez, MD, and Mara Sarruf, have concluded that it is imperative for parents to recognize hearing-loss symptoms and ear discomfort in their children with Down syndrome. A disorder called secretory otitis media, inflammation of middle ear mucosa (often accompanied by excess fluid and secondary eustachian tube obstruction), is believed to be a leading cause of hearing loss in people with Down syndrome. Therefore, early detection of the warning signs of hearing impairment should be identified so that early treatment

continued on page 36

On His Way To A Brighter Future

Michael is an inquisitive boy with mental retardation. His behavior kept him from making progress in public school. His frequent hitting, biting, and noncompliance pulled him further and further behind, and no one knew how to get him back on course.

When he came to Heartspring School at the age of 10, we started by getting to know him as an individual. His interdisciplinary team gathered data on his behavior in every situation, throughout the day. We documented causes and correlations.

Patterns began to emerge. Michaels toughest challenges, it turned out, lay in making transitions between tasks, so we provided him with structure and predictability. He was a boy of many hobbies, so we reinforced appropriate behaviors with rewards that reflected his personal interests. He had fallen into a cycle of frustration that tended to snowball out of control, so we taught him practical strategies dealing constructively with his anger.

Now, just over a year later, Michael is realizing a fuller potential. He's happier. His frequency of problem behaviors has dropped from 85 percent to nearly zero. He's returned to public school – and is once again moving forward with his life.

If you know a child who could use some help getting back on course, call Heartspring School.

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Circle #42

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can occur. This study was presented at the American Academy of Otolaryngology—Head and Neck Surgery Foundation Annual Meeting and Oto Expo in September 1999.

RARE DISEASES UPDATE

Neurotransmitter disorders: An underrecognized group of disorders

Research done by Keith Hyland, PhD (director of Neurochemistry Laboratory at the Kimberly H. Courtwright and Joseph W. Summers Institute of Metabolic Disease, Baylor University Medical Center, and K. Michael Gibson, PhD, SACMG, associate professor molecular and medical genetics and pediatrics, and director of Biochemical Genetics Laboratory, Oregon Health Science University Research), indicates that many children who are diagnosed with cerebral palsy, autism, seizure disorders, and mental retardation and other developmental delays may potentially have a disease of neurotransmitter metabolism. These diseases include: GTP Cyclohydrolase I Deficiency (dopa responsive dystonia) and Tyrosine Hydroxylase Deficiency (both currently treatable), Aromatic L Amino Acid Decarboxylase Deficiency, and Succinic Semialdehyde Dehydrogenase (SSADH) Deficiency. However, due to lack of information about and rarity of these diseases, the specific testing that exists for them is seldom done. The result is that many children may remain misdiagnosed and improperly treated. For further information, contact the Pediatric Neurotransmitters Disease Association at (516) 937-0049; or visit their Web sites at http://www.aladd.com and http://www.tndassoc.org.

MENTAL RETARDATION

Rett Syndrome Gene Identified

Fourteen years of research has yielded the location of the gene for Rett syndrome, one of the most common causes of mental retardation among girls. Uta Francke, MD, profess of genetics at Stanford University Schoo Medicine, and Mimi Wan, MD, PhD, also o the university, are coauthors of a study that reports the gene's location on the X chromosome. The gene takes part in halting the production of important—yet unidentified—proteins, which leads to the deterioration of the nervous system (a characteristic of the disease). The discovery of this gene makes early diagnoses possible and potentially provides doctors with the means to assuage or stall the effects of the disease in the child. This study is published in the October issue of *Nature Genetics*.

SICKLE CELL ANEMIA

Ultrasound to Detect Stroke Risk

Using sensitive new ultrasound equipment, doctors are now able to get a clear picture of the blood flow in the arteries of children with sickle cell anemia (an inherited, chronic blood disease), identifying abnormalities that may precede a stroke. With this technology, the narrowing of the arteries that occurs in the head (10 to 12 percent of children with sickle cell are at risk for this abnormality) is now easily recognized and can be treated more appropriately. Says Ab Malouf, Jr., MD, assistant professo radiology at the University of Mississ Medical Center, and head of the stu "Ultrasound with power Doppler is noninvasive, and it is much less expensive." **EP**

Editor's Note: Starting this month, EP will be publishing medical research updates on a continuous basis. This column will feature research sponsored by the National Institutes of Health, as well as those reported in medical journals. All material in this column will be thoroughly reviewed by our medical advisory board before publication i order that they may verify the integrity an validity of the research each study conta

With the spate of research coming fro the medical field and reported in the newspapers these days, it is difficult for the average person to decipher which studies are biased and which ones are genuinely reliable. To best serve our readers, we will make a systematic effort to go directly to the source of each piece of research we receive, and print only what we consider to be the most reliable. DC

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Circle #41

DEFINING MEDICAL NECESSITY

Strategies for Promoting Access to Quality Care for Persons with Developmental Disabilities, Mental Retardation, and Other Special Health Care Needs

A report prepared by

Henry T. Ireys, PhD, Elizabeth Wehr, JD, and Robert E. Cooke, MD

WHAT IS THE PROBLEM?

In managed care plans, access to service depends in part on whether a service is found to be "medically necessary." Many existing definitions of medical necessity may lead to the denial of services required by special populations, including children, youth, and adults with developmental disabilities, mental retardation, serious emotional disorders, or other special health care needs. Most definitions lack critical components that will promote appropriate care for this population.

WHAT IS OUR GOAL?

The full Definition of Medical Necessity report (1) outlines a strategy for defining medical necessity that will promote high-quality care for children, youth, and adults with developmental disabilities, mental retardation, serious emotional disorders, or other special health care needs, and (2) included a draft definition that can be incorporated into legislation, regulation, or contracts. The report consolidates diverse components into a single statement with practical implications and presents a framework useful for analyzing definitions of medical necessity.

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Specifications for Defining Medical Necessity

1. A covered service or item is medically necessary if it will do, or is reasonably expected to do, one or more of the following:
    - Arrive at a correct medical diagnosis[1]
    - Prevent the onset of an illness, condition, injury, or disability (in the individual or in covered relatives, as appropriate)[2]
    - Reduce, correct, or ameliorate the physical, mental, developmental, or behavioral effects of an illness, condition, injury, or disability
    - Assist the individual to achieve or maintain sufficient functional capacity to perform at age-appropriate or developmentally appropriate daily activities

2. The managed care organization (MCO) or insurer must determine medical necessity on the basis of health information provided by the following persons: the individual (as appropriate to his or her age and communicative abilities), the individual's family, the primary care physician, and consultants with appropriate specialty training, as well as other providers, programs, multidisciplinary teams, educational institutions, or agencies that have evaluated the individual.

3. The determination of medical necessity must be made on an individual basis and must consider
    - The functional capacity of the person and those capacities that are appropriate for persons of the same age or developmental level
    - Available research findings, health care practice guidelines, and standards issued by professionally recognized organizations or government agencies

4. Final determinations will be made by a physician in concert with the following persons: the individual's primary care physician; a consultant with experience appropriate to the individual's age, disability, or chronic condition; and the individual and/or family.

5. Medically necessary services must be delivered in a setting (e.g., an individual's home, school, child care center, workplace, or community-based agency) that is appropriate to the specific health needs of the individual.

[1] Unspecified or undiagnosed conditions are common in this population; hence, additional or special diagnostic procedures or tests are frequently needed to reach a diagnosis that will assist in determining an appropriate care plan.

[2] Knowledge about the role of genetics in chronic disease and disability is growing rapidly. For example, diagnosis of fragile X syndrome in a child requires pedigree analysis and laboratory studies not only to permit accurate diagnosis, but also to ensure that genetic counseling is provided to help individuals and families make informed choices on reproductive issues.

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WHAT IS IN OUR REPORT?

Our report explains the rationale for a comprehensive approach to defining medical necessity. It illustrates the organizational context of medical necessity, and it distinguishes medical necessity from rationing. The report also outlines criteria for evaluating definitions of medical necessity:

1. The definition should incorporate appropriate outcomes within a developmental framework.

The Joseph P. Kennedy, Jr. Foundation Medical Necessity

The Joseph P. Kennedy, Jr. Foundation has for many years dedicated its resources to improving the lives of persons with mental retardation and other disabilities. Promoting access to their health care of high quality is one of the Foundation's most important goals.

Children and adults with mental retardation and other disabilities now are obtaining health services through MCOs. These institutions have the responsibility for identifying and supporting medically necessary health service. The definition of "medical necessity" serves an extraordinarily important purpose because it establishes the foundation for deciding what services each person will receive.

The Foundation wants to promote definitions of medical necessity that are sufficiently well-formulated and comprehensive to meet the health needs of persons with mental retardation and other disabilities. As MCOs and insurers seek innovative ways to meet the needs of all enrolled groups, model criteria for definitions of medical necessity are absolutely essential.

This report provides an exceptionally strong rationale for a comprehensive approach to defining necessity, as well as practical language that can apply to diverse purposes.

2. The definition should explicitly address the information needed in the decision-making process.

3. The definition should identify who will participate in the decision-making process

4. The definition should refer to specific standards.

5. The definition should support flexibility in the sites of service delivery

Based on guidance from a steering committee and a diverse expert panel, we developed specific wording for defining medical necessity. The report discusses the implications of implementing this approach.

WHO IS OUR AUDIENCE?

Vigorous dissemination efforts will ensure that this report reaches a broad range of

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legislators and legislative staff, consumers, health care professionals, health plan administrators, and researchers.

Single copies of the executive summary (L097) and the full *Defining Medical Necessity* report (L071) are available at no cost from:

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Development of the report and summary was supported by the National Policy Center for Children with Special Health Care Needs and the Joseph P. Kennedy, Jr. Foundation. The Center is funded through cooperative agreement 24MCP from the U.S. Department of Health and Human Services, Health Resources and Services Administration's Maternal and Child Health Bureau. **EP**

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Robert E. Cooke, MD, is Emeritus Professor, Dept. of Pediatrics, State University of New York, Buffalo, and Former Pediatrician and Chief, Johns Hopkins Hospital.

"I am delighted that the Joseph P. Kennedy, Jr. Foundation was able to assist in supporting this work, and I am confident that it will be useful to everyone who is working to promote high quality of health care for persons with mental retardation, other disabilities or special needs."

Eunice Kennedy Shriver

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TEEN EXPEDITION:
A program for teens which will allow them to experience supervised, independent travel.

OUTDOOR ADVENTURES:
A week-long sleep away camp experience for children/adolescents with physical disabilities.

CAMPOREE/UNDER THE UMBRELLA:
Arts, crafts, sports, cooperative games, music, and special activities for children who have physical disabilities, PDD (autism) or AD/HD.

CAMP CHATTERBOX:
An overnight, intensive therapy camp for non-speaking children and adolescents who use augmentative and alternative communication systems and a training program for their parents.

MOVERS AND SHAKERS:
A sensory motor group program of occupational, physical, and speech therapy activities for children with developmental delays.

CHAT AND SNACK:
An oral motor, group program of exercises to strengthen and improve movements for talking and eating.

KUNG FU/KARATE:
Martial arts instruction for children with AD/HD, cerebral palsy, or any diagnosis causing gross motor or fine motor problems.

DEVELOPMENTAL DANCE:
A dance program for children with any diagnosis causing gross motor, fine motor, or social interaction delays.

READY, SET, SCHOOL:
A program to enhance pre-writing skills for children with fine motor difficulties.

PALS PARADISE:
Creative arts, drama, martial arts, and crafts for children with physical or developmental disabilities.

THERAPEUTIC HORSEBACK RIDING:
A program for children and adolescents with physical disabilities or movement dysfunction.

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Circle #28

Adapting Toys For All Kids

by The Let's Play! Project

Toy features to look for as well as materials that can be used to make toys easier to play with

During the first years of life, the roles of children are characterized by play. They actively explore and interact with people and objects in their world. Mouthing, banging, touching, grasping, holding, rolling over, and clapping are just a few of the activities which furnish the child with information about the world. During the early years language emerges and play moves through stages, from exploration to using objects to pretend and mimic activities in the world.

Toys are the tools used by children during these developing years. However, many children are limited in the toys they can use. Often parents of children with disabilities are not sure which toys to choose. These parents tell us:

"I'm not sure what toys to buy. I can't just walk into a toy store and choose a toy; she can't play with just anything..."

"Our other children seemed to know what to do when they played. How can we get Anna to play?"

"We don't have much time for play; we have therapy to do and goals to work on"

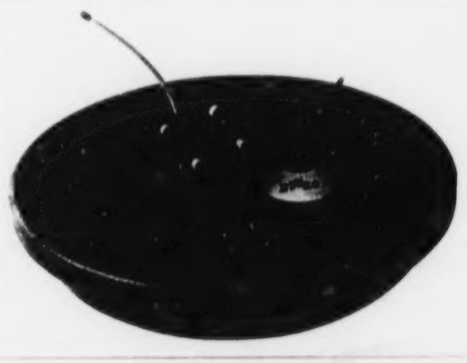
It makes sense to start where kids are successful- with toys that they like and can interact with. The Let's Play! Project Staff has found that two things must be considered in selecting toys for any child, :

1. What does the child like? What is she interested in?

2. How can the toy be used? What can the child do to play with it?

Remember, it is not the toy that is important, but how the child interacts with it. There are several adaptations that can be applied to make a toy more fun!

Austin is better able to play with this toy because it does not move away from him. Now he does not get frustrated while exploring the different buttons.



Suzie loved playing with the hippo that she controlled with a separate button controller—it was noisy and fun! But it moved so fast, she could not follow it. By putting the toy in a base, it stays where she can see it and still make it move!

Adapting Toys

As parents tell us they prefer to purchase toys from local stores, simple adaptations to the toys can make them easier for a child to use. These solutions include ways to extend, stabilize and make toys easier to use; the toy's accessible features and the abilities of the child will guide the modifications. The

Links can be used to "anchor" a toy to a tray so that it can not get "lost." The child simply pulls up on the links to retrieve the toy.

Toy Features

For the past decade, government mandates to ensure safe toys have lead to toys designed with simple features and easy access options. Buttons are larger, colorful plastics are used instead of metal, different textures abound, and sounds are often incorporated. The advent of the microchip has increased the availability of inexpensive toys that are highly reactive when touched—providing maximum enjoyment with minimal input.

When looking for toys, try them out before you buy. It is important to consider the features that will appeal to your child, how the toy is used and the physical construction of the toy. Listed below are specific elements to look for.

Sensory Characteristics: Many toys include several characteristics that may or may not be appealing to your child. Consider your child's preferences as well as your own. What a child likes may not be the same as his/her parent's. Some things to keep in mind are listed below:

Sound: Does the toy make sound? If so, is the sound potentially calming, or louder and potentially arousing? Can the sound be startling? Is the tone of the sound harmonic or brassy? Does it have a volume control? How long after activation does the sound continue?

Visual: Is the toy attractive? Is the color of the toy bright and/or is there high contrast between the colors? Are the color patterns simple or complex? Do the visual features invite touch? If the visual features are lights, how are they activated? How bright are they? Are they linked to sound? Can they be disconnected from sound?

Touch: What does the toy feel like? Is it soft, hard, smooth, rough, tickly, or cuddly? Is there vibration? Is the touch likely to be startling? Does the touch promote grasp? release? Does the feel of it encourage active exploration? If so, with the whole hand or with isolated finger movements?

Access Considerations: When a child is unable to interact with a toy, he or she may become frustrated or disinterested. Examine the toy to see how easy/hard it is to use.

How is the toy activated? Does activation require minimal movement, or more, on the part of the child? What movements are required? What body parts can activate the toy?

Where must the toy be positioned for activation? Can the position be changed to meet the needs of the child? Will the toy still "work"?

Does the toy have handles or knobs which the child must use? Are they of an appropriate shape and size for this child? If they are not, can they be easy adapted?

Are there multiple parts to the toy which need to be activated? Are these multiple parts inter-related in such a way that all must be activated to make the toy interesting? Alternatively, can multiple activation points be operated independently to provide variety?

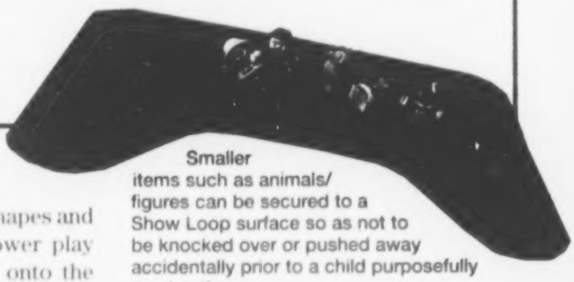
Physical Characteristics: Durability and safety should be incorporated into the design of the toy. Consider where your child will most likely use the toy.

Size: Small toys may in inaccessible to children with unrefined hand skills, or limited motor control; large toys may be inappropriate for placement on a lap tray, table or small bench. What are the physical characteristics of this toy? And where will the toy be used?

Construction: How is the toy put together? Is it stapled or glued? What is it made of? These factors may influence the safety, weight or durability of the toy/device.

Stable: Is the toy stable by itself? Does it require one hand to stabilize it while the other hand manipulates it?

Versatile: Does the toy provide some variety in and of itself that may promote use of the toy in more advanced ways as the child develops skills?



Smaller items such as animals/ figures can be secured to a Show Loop surface so as not to be knocked over or pushed away accidentally prior to a child purposefully moving them.

Tyler's shopping cart helps him to walk "all by himself" when Velcro™ is applied to each wheel. It adheres to the loop carpet to slow his cart down. This makes walking feel safer and more fun to him. His dad plans on removing the Velcro™ wheel-by-wheel as Tyler begins to walk better!

following are examples of toy positioning and access aids.

- Links come in a variety of shapes and sizes and can be used to lower play materials from an overhead onto the child's body for initial "connection."

Sometimes children are so intrigued by the links themselves that they never get to the toy at the end! Assuming that the toy is more interesting than the links, try using or inch elastic for a pulling effect, shoelaces (straight or curly), or snap straps (in sewing stores for toddler pants).

Stabilizers are materials that support play by preventing an item from moving out of the child's visual or physical reach.

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adapting toys for all kids

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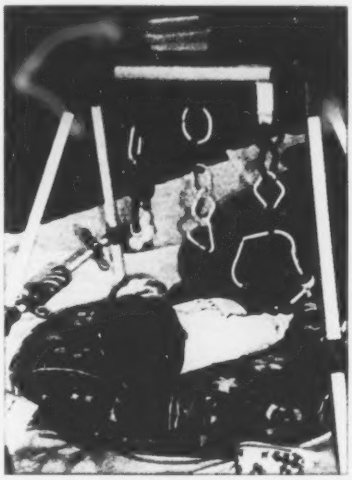
Often toys need less adaptation if they can stay "in one place".

Non-slip materials: are readily available which prevent an object from moving out of reach. Materials such as dycem (from professional catalogs) or grip liner. "mug mats" and other kitchen products can be used.

Velcro™: Small strips of (male/hook) Velcro™ can be placed on the base of a toy to hold a toy firmly in place. It adheres to a matching (female/loop) Velcro™ strip on the table surface where it can be played with.

Show Loop is a fabric which acts as "female velcro". When glued to a play surface (tray, table top, etc.), objects will firmly adhere to it when "male velcro" is placed on the bottom of the object. For example, by putting strips of male Velcro™ on the base of a puzzle, the child can more easily use the pieces, as the puzzle is stationary.



Attachers are materials that are used to bring items closer to the child, making reaching, grasping and playing less "work." Families frequently use attachers with an overhead gym to make play easier. Several items are available for use.

If you need a playing surface for stabilizing objects, bed trays can be used as floor tables and covered with Show Loop.

- Carpet squares (indoor/outdoor) provide some stability and also work with male Velcro™, but objects do not adhere as strongly as with Show Loop.
- Dual Lock is another material that is stronger than Velcro™, but not as easily removed.

Velcro can also be placed on other toys/objects to promote stability.

- Built-Up Extenders: Building up or extending existing parts on toys is another method of adaptation that can lead to more successful use.
- Cylindrical foam padding comes in a variety of colors and widths and is a "quick-fix" to make crayons, markers, spoons and musical instruments easier to use. Sponge rollers can often be used in the same way.
- Large knobs can be found in hardware

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stores to replace smaller ones. This can be particularly helpful for puzzle adaptations. Popsicle sticks or tongue depressors can be glued onto piano keys to provide easier access.

- Confinement Materials: Some toys or pieces to toys have a tendency to "move away" from a child. To keep the toys in visual and/or physical reach, use items such as hula-hoops, box tops or planter bases. This also helps a child to control his immediate play environment.

[illegible]

Often the use of one or several of these simple adaptations to a well-selected toy provides new and unique opportunities for play by children with disabilities. Go to the Let's Play! web site for more ideas. (http://cosmos.ot.buffalo.edu/letsplay/) **EP**

The Let's Play Project is part of the Center for Assistive Technology, State University of New York at Buffalo, NY, 515 Kimball Tower, Buffalo, NY 14214; phone: (716) 829-3141; fax (716) 829-3217.

RESOURCES

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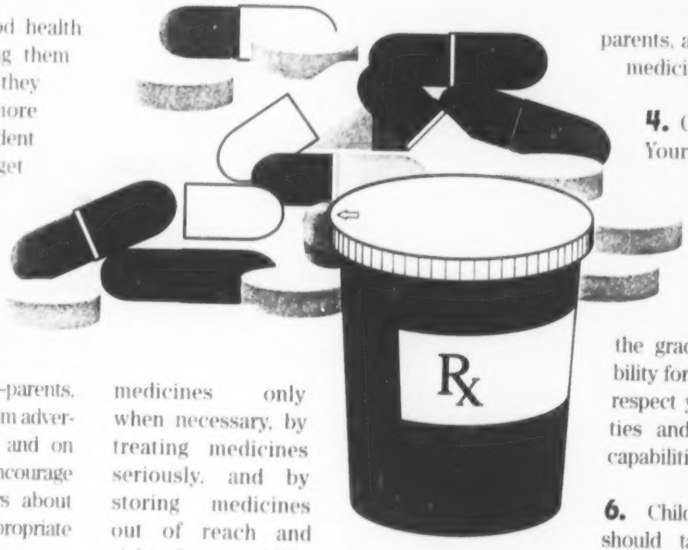
Help Your Children understand their medicines

Teaching your children good health practices includes teaching them about medicines. The more they know about medicines the more prepared they are for independent and responsible use as they get older. Children need to know about how medicines work in the body.



What do children want to know?

Children need to learn about medicines from trusted sources—parents, physicians, or teachers instead of from advertisements in stores, publications, and on television. As a parent, you can encourage your children to ask the doctors about medicines and help them prepare appropriate questions. For example:

- What will my medicine taste like?
- How will it make me feel better?
- Will it be pills, liquid, or shots?
- When do I have to take it?
- How long do I have to take it?
- Does it have side effects?
- Why do I have to take it?

What you should teach your children to do:

- Take the right medicine, at the right time, in the right amount—read the directions with your child.
- Take all of the medicine prescribed even if your child feels better. This is especially important when taking antibiotics.
- Encourage your child to tell you about any unexpected side effects or reactions so you can call a healthcare professional.

Participate in health education activities that teach the principles of responsible use of medicine.

Parents and caregivers

Most of all, as a parent, set an example of proper and safe medicine use by taking medicines only when necessary, by treating medicines seriously, and by storing medicines out of reach and sight of young children.

Ten principles for teaching your children and adolescents about medicines

These principles are intended to encourage activities that will help your children through adolescence, become active participants in the process of using medicines * to the best of their abilities. These principles do not specify children's age, as children of the same age vary in level of development, experience, and capabilities.

1. Children, as users of medicine, have a right to appropriate information that reflects their health status, capabilities and culture.

2. Children want to know. Healthcare providers and health educators should communicate directly with children about their medicines.

3. Children's interest in medicines should be encouraged. Show them how to ask questions of healthcare providers, parents, and other caregivers about medicines and other therapies.

4. Children learn by example. Your actions should show children appropriate use of medicines.

5. You, your children and your healthcare providers should negotiate the gradual transfer of responsibility for medicine use in ways that respect your parental responsibilities and health status and the capabilities of your child.

6. Children's medicine education should take into account what children want to know as well as what health professionals think children should know.

7. Children should receive basic information about medicines and their proper use as a part of school health education.

8. Children's education about medicine should include information about their general use and misuse, as well as about the specific medicines the child is using.

9. Children have a right to information that will enable them to avoid poisoning through misuse of medicines.

10. Children asked to participate in clinical trials (after your consent) have a right to receive appropriate information to promote their understanding before assent and participation.

Adapted from U.S. Pharmacopoeia's Guide to Educating Children About Medicine.

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*Medicines include all types: prescription medicines, non-prescription medicines, herbal remedies and nutritional supplements, such as vitamins and minerals. **EP**

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Circle #16

An Introduction to State Title V Programs for Children with Special Healthcare Needs

WHAT IS TITLE V AND HOW CAN IT HELP YOU?

by John Reiss, PhD

Every state and the District of Columbia has a Title V Program for Children with Special Health Care Needs (CSHCN) that is funded, in part, through the Federal Title V Maternal and Child Health Block Grant, and provides health and support services to children with special needs and their families.

These programs began in 1935, when Congress passed the Social Security Act, a law designed to bring some financial and health security into the lives of America's most vulnerable citizens. The fifth article of that act, known as Title V, provided funds to states to develop and operate public healthcare programs for certain children with special healthcare needs, as well as to establish other programs to promote the health of mothers and children with low income.

In the 1930s through the 1970s, most of the state programs that were funded through Title V of the Social Security Act were called Crippled Children's Services (CCS) Programs and focused their efforts on identifying "crippled" children and providing services for the diagnosis, treatment, and ongoing care of "crippled" children. Children initially served through these programs were limited to those with orthopedic problems. In the 1960s, 1970s and 1980s there was a gradual expansion of these programs in many states, and state Title V CCS Programs began to provide health and related services to children with other serious chronic health conditions and physical disabilities, such as cerebral palsy, heart problems, hearing problems, spina bifida, cystic fibrosis, etc. In the late 1970s, Congress funded state CCS Programs, through Title V, to provide case management and care coordination services to children under the age of 16 who received benefits through the Supplemental Security Income (SSI) Program.

As a result of the expansion of the eligibility criteria of state CCS Programs, services for more children with chronic illnesses, developmental disabilities, sensory impairments, and other special health needs were being provided. In recognition of this expanding responsibility and in response to criticism that the term "crippled children" was stigmatizing, Congress changed the name of its program in the Title V statute to State Programs for Children with Special Health Care Needs (CSHCN). In response to this change in federal legislation, all states' Title V Programs have deleted the phrase "crippled children" from their names. However, because the legislation did not mandate that states use a specific name, Title V CSHCN Programs are known by different names in different states. Names given to CSHCN Programs include: "Children's Medical Services;" "Children's Special Healthcare Services;" "Child Health Specialty Clinics;" and "Division of Specialized Care for Children."

The federal Title V legislation also gives states the flexibility to use their Title V funds to design and implement direct care programs and services that are responsive to the specific needs of CSHCN and their families in the state, and accommodate the strengths and limits of the child health infrastructure in the state. Therefore, state Title V CSHCN Programs have different financial eligibility criteria, serve different populations of children and youths with special healthcare needs, and provide and/or fund different sets of

> **Over the last ten years, the Maternal and Child Health Bureau, at the Federal level, in partnership with state Title V CSHCN Programs, family leaders, and other professional and advocacy organizations have focused a significant level of effort on defining, describing, and making family-centered, community-based care available to all CSHCN and their families.**

healthcare and related services. This can be confusing for a family with a child who has special health needs, when moving from one state to another.

Because of the significant differences among state Title V CSHCN Programs, the Maternal and Child Health Bureau has supported the development of the "Directory of State Title V CSHCN Programs: Eligibility Criteria and Scope of Services" through a grant to the Institute for Child Health Policy at the University of Florida. The information contained in this report is available through the Internet. The address on the World Wide Web is http://www.ichp.edu.

In addition to providing direct, personal healthcare services to eligible children, state Title V Programs also have a responsibility to improve the quality and responsiveness of the overall healthcare system for children with special healthcare needs. States were given this "systems development" responsibility in 1989, when Congress amended Title V of the Social Security Act, and required that state CSHCN Programs "provide and promote family-centered, community-based, coordinated care (including care coordination services...) and facilitate the development of community-based systems of services for such children and their families."

The 1989 amendments also allowed state Title V Programs to continue to use federal funding to provide rehabilitation services to children under the age of 16 who receive benefits through the SSI Program.

Over the last ten years, the Maternal and Child Health Bureau, at the federal level, in partnership with state Title V CSHCN Programs, family leaders, and other professional and advocacy

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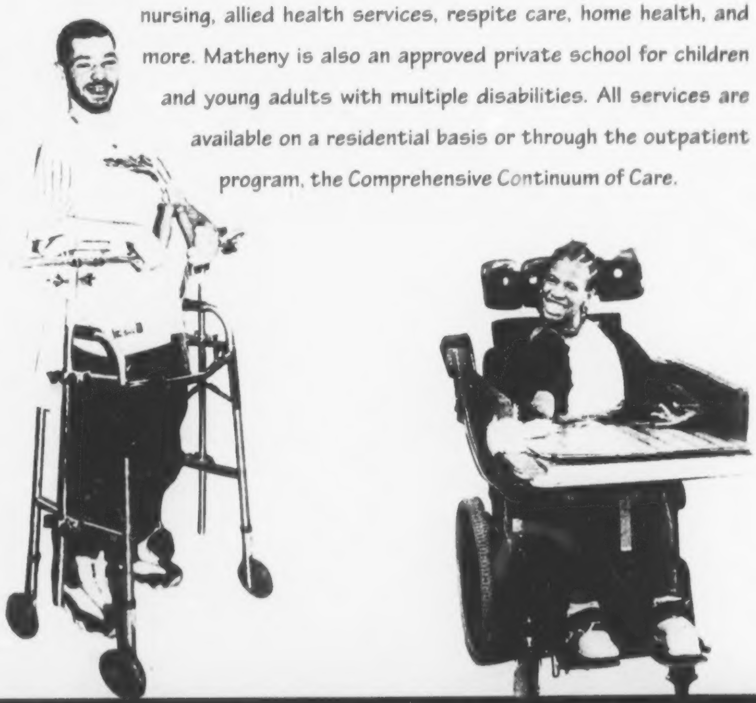
Matheny, a hospital for habilitation, offers health care services for people of all ages with developmental disabilities. Services include medical, nursing, allied health services, respite care, home health, and more. Matheny is also an approved private school for children and young adults with multiple disabilities. All services are available on a residential basis or through the outpatient program, the Comprehensive Continuum of Care.



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organizations, has focused a significant level of effort on defining, describing, and making family-centered, community-based care available to all CSHCN and their families.

Family-centered care is a process that focuses on ensuring that:

- the organization and delivery of healthcare services meet the emotional, social, and developmental needs of children:
- the families of CSHCN are integrated into all aspects of the healthcare plan:
- families have alternatives and choices based on their own needs and strengths, and receive support for those choices:
- the healthcare system facilitates family/professional collaboration at all levels, especially in planning, implementing, and evaluating programs and their related policies and practices.

To accomplish this, state Title V CSHCN Programs have worked to develop meaningful partnerships with families and promote leadership by families.

State programs also provide the training, guidance, and policies that create these partnerships within each community as it builds its systems and services. Thus, the activities of state Title V CSHCN Programs are not limited to providing and paying for healthcare for eligible children.

Rather, these programs also fund family-to-family support organizations and help families in their effort to play an active role in the development of programs and policies that are of benefit to all children with special needs and their families.

Rather, these programs also fund family-to-family support organizations and help families in their effort to play an active role in the development of programs and policies that are of benefit to all children with special needs and their families. **EP**

John Reiss, PhD, is the Director of Policy and Program Affairs at the Institute for Child Health Policy (ICHP), University of Florida, Gainesville, FL. For a listing of Title V Programs by state, see the Exceptional Parent 2000 Resource Guide or log on to the ICHP Web site: http://www. ichp.edu.

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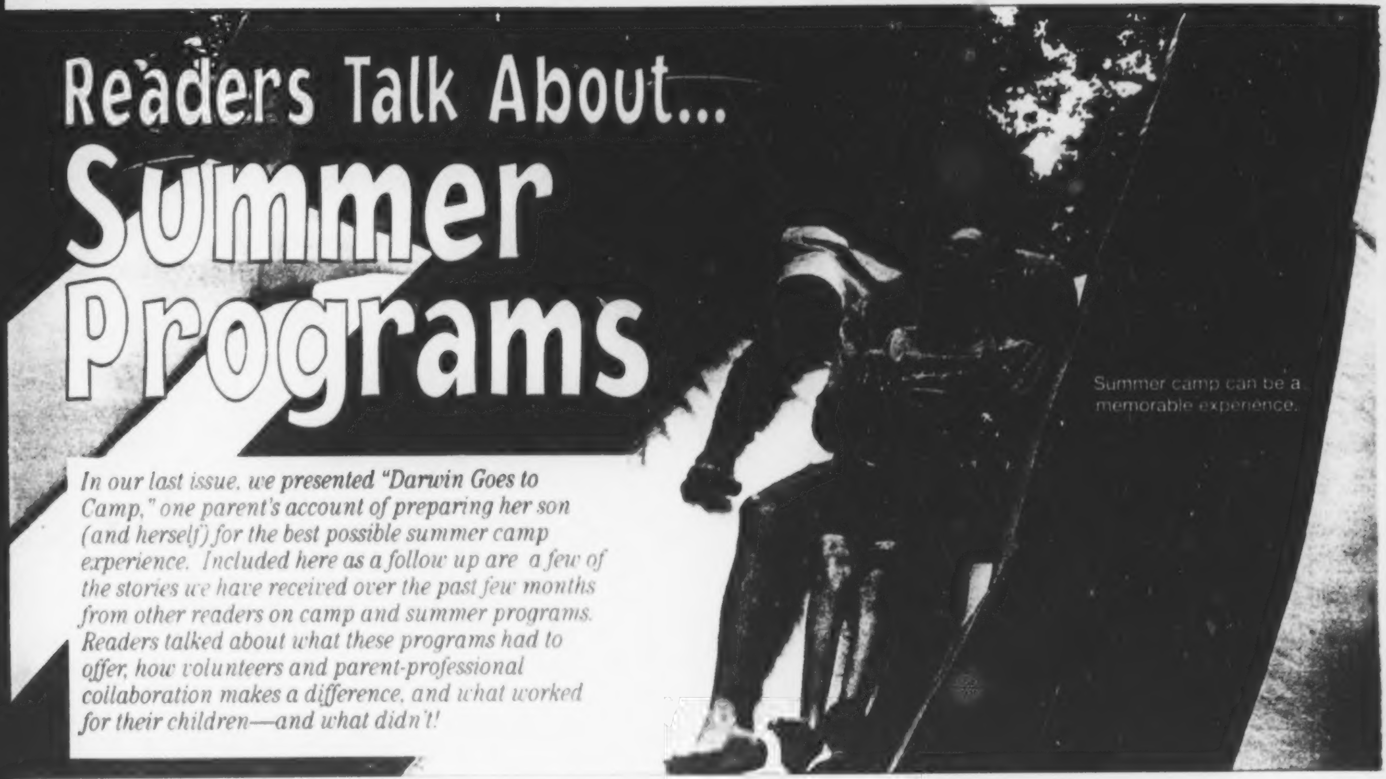
Circle #73

Readers Talk About... Summer Programs



Summer camp can be a memorable experience.

In our last issue, we presented "Darwin Goes to Camp," one parent's account of preparing her son (and herself) for the best possible summer camp experience. Included here as a follow up are a few of the stories we have received over the past few months from other readers on camp and summer programs. Readers talked about what these programs had to offer, how volunteers and parent-professional collaboration makes a difference, and what worked for their children—and what didn't!

To Summer Camp or Not... That Is the Question

by Jamie Sowers

With ten years experience as a parent of a daughter, Rebecca, who has cerebral palsy, I realized a few years ago that it is all right to need a break. I also have a little boy, Ryan, who is three years younger than Rebecca. I sometimes need a break from him, too!

I looked into camps that could suit both of my children's needs. I am a firm believer in inclusion and mainstreaming in the schools, so why not in a camp? The camp I found had just that: programs for a younger child and programs for a child in a wheelchair. The camp had sent us information through our school, and would even provide transportation for a nominal fee if we needed. It had a lot to offer, so I called and was allowed a tour of the facilities. I also asked if they would have a problem if I stayed for three days. I didn't bother anyone and stayed out of the way of the campers, volunteers and counselors, but I had to make sure everyone was taken care of.

The camp was wonderful—accessible, lively, many activities to do, wonderful people (campers and counselors and volunteers), all the things you could want in a camp. At the time, Rebecca was being catheterized four times daily and that was a major issue for me; however, there was a nurse on staff who could accommodate that. Then there was the feeding issue. I made sure I packed a lunch that would be easy for a new person to feed her. Most of the volunteers were teenagers with no previous experience handling or feeding people with special needs, and Rebecca was assigned a different person every day. I watched a 14-year-old boy try to feed Rebecca. He was getting frustrated, and so was she. I wound up feeding her lunch.

Another problem was the fact that most of the campers with disabilities were in wheelchairs. Ever sit in a wheelchair in 90 degree weather with that black, no-breathing leather underneath you for six hours? Well, these kids did. They were taken out of their chairs only once to go swimming. That job (transferring kids in and out of their chairs to get bathing suits on and off) is a major task toundertake. So again, I watched, thinking that this was not working out.

I went and looked in on Ryan. He seemed to be having a great time, and although Rebecca looked like she was enjoying some of the activities (she enjoyed the arts and crafts, swimming, and socializing the most), it was very draining for her to be out in the heat all day long.

I am a great believer in having options, so I tried to think about what options were available and what would work best for us. How would Rebecca (and I) be able to enjoy camp without all the hassle? After three days, I realized that Rebecca should go for half days, after lunch...that way she would

continued on page 50

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Circle #51

Summer camp counselors are dedicated to making the camp experience both educational and fun.

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already have had lunch, been cath'd, had plenty to drink, plenty of down time, and be ready for a few hours of fun. That worked perfectly. So, we tried it that way and we liked it.

The Broome-Tioga BOCES Integrated Summer School Program

by Carla Simpson, MSW, CSW

Children with autism and other severe developmental disorders need ongoing therapy and education to maintain their skills. Communication and social skills are particularly susceptible to regression. So, how do we help these children maintain their skills over the summer? Summer camp. Well, actually an inclusive summer school program run at summer camp sites, integrating these students with their non-disabled camping peers.

Spearheaded by parents from the local Autism Society of America, the Broome-Tioga BOCES started an Autism Task Force comprising administrators, education staff, and social workers. The task force worked on ways to improve educational programs for students with autism in the BOCES districts. The task force created a new, totally integrated summer program for autistic and multiply disabled students.

Community camp sites included the Jewish Community Center, Binghamton YMCA Summer in the City Program, Heritage Country Club, and Great Beginnings Child Care Center. The students, their teachers, and aides joined in all of the camp activities, including swimming, sports, crafts, and field trips. Many of these activities were challenging for the students with disabilities, some of whom had sensory integration or mobility problems. Each student, however, was able to participate in the activities at his/her own level. Individual Education Plan objectives included communication, social skills, adapted switch use and other skills, depending on the student's needs and level of accomplishment.

Campers at Extra Special People, Inc., are always busy. Here they take a rare break to pose for a group shot.

Sometimes, the Campers Make the Camp!

by Susan Colburn

Every summer, members of our church take about 150 fourth- to sixth-graders camping for a week. Shocco Springs Camp in Talladega, AL, is a huge facility, built on a hill.

This summer, for the first time, my son, Ryan, and one of his friends, also named Ryan, went along on the trip. Unfortunately, the camp was not accessible at all. This was a challenge, because both boys use wheelchairs. Thanks to the great attitude of all the adults and children involved, the issue of accessibility became a non-issue. The theme for the camping trip that year was "Teamwork." What better way to demonstrate the meaning of teamwork than by coming together to help others have the best time possible? All of the other campers made sure the two Ryans were part of every activity. Both boys slept in a cabin with 14 other boys, and participated in all activities, from swimming and canoeing, to arts and crafts, and, of course, the annual watergun fight! They even received love letters, which were read aloud at lunchtime!

I had visited the camp beforehand and had grave misgivings about Ryan going on the trip. I felt anxious, but Ryan really wanted to go, so I let him. It turned out be a lot of fun for everyone.

This experience has certainly changed the way that the children who went on the trip see people with disabilities. It has also opened up a whole world for my son. He is very proud of his accomplishments while camping, and had a great time. As a parent, I think it has made him more outgoing, self confident, and it did so much for his self-esteem. He is eagerly awaiting his next opportunity to go on a church trip!

Jamie Sowers writes that it is all right to need a break from caring for her daughter Rebecca (front) and son Ryan.

Both the BOCES and camp staffs were trained in issues surrounding autism and related disorders by parents from the Autism Society of America. A school nurse participated, even going on field trips, so that students who were tube fed could be fully included. This program was unlike any other program in New York State in its use of existing camp programs for integrated education sites. It was well received both by parents and the community.

Broome-Tioga BOCES has made a real commitment to working with parents to find the best options for educating their children. This inclusive program is an example of parent-educator collaboration at its best.

An Extra Special Camp

by Carol Brooks

My son Craig is 13 years old, visually impaired, and has a seizure disorder, severe developmental delays, and an oral-motor dysfunction that affects his eating and swallowing.

When Craig was 7 years old, I had come home from the birth of my daughter, and was feeling overwhelmed. I asked the state about a summer program Craig could attend. The state offered to pay tuition for a county-run program at a state recreational facility. He would have been in a group of about 10 other children. Nearby, however, was a program called ESP (Extra Special People), Inc., that offers leisure activities for children with disabilities ages four through adult. They seemed to have more to offer, so I enrolled

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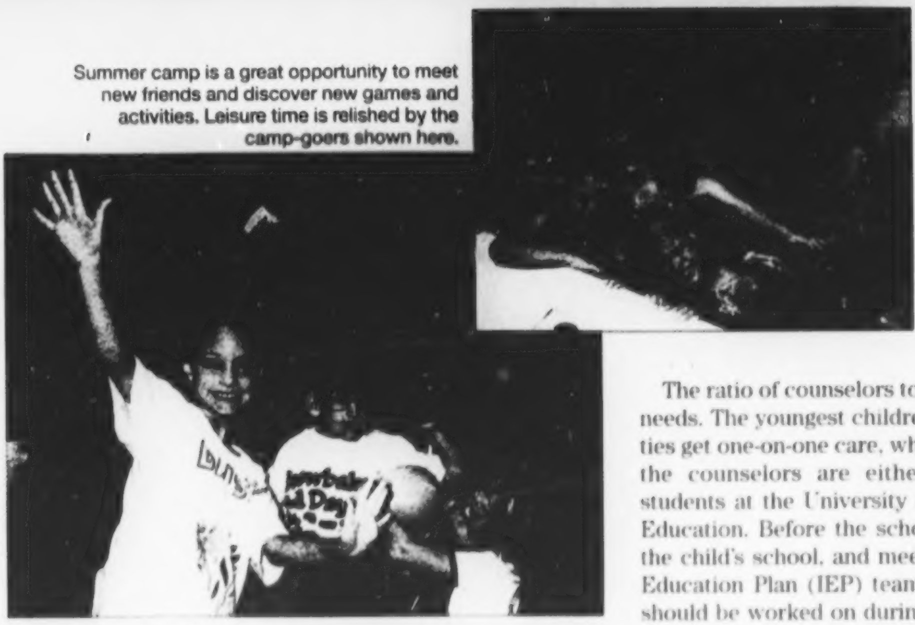

Summer camp is a great opportunity to meet new friends and discover new games and activities. Leisure time is relished by the camp-goers shown here.

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Craig. He has been going to ESP ever since.

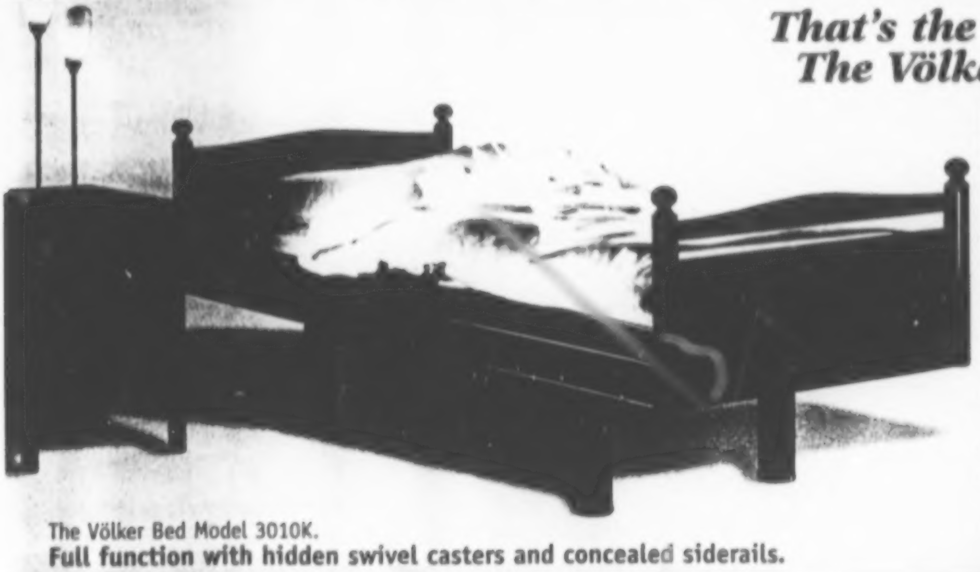
Although ESP has programs throughout the year, the summer program runs for about eight weeks, five days a week, from 9:00 a.m. to 3:30 p.m.--for $40 a week!

ESP features bowling, visits to the community library, school bus service, and access to all local parks, including a nature center and a lake. Summers in Georgia get hot, and the campers get to swim every day. The camp offers a very structured routine, including art, sports, music, games, and leisure play on a playscape with swings. The campers are always busy doing something fun!

The ratio of counselors to campers depends on the child's needs. The youngest children, or those with severe disabilities get one-on-one care, which is what Craig needs. Most of the counselors are either graduate or undergraduate students at the University of Georgia, majoring in Special Education. Before the school year ends, counselors go to the child's school, and meet with his or her Individualized Education Plan (IEP) team, to see if there are areas that should be worked on during the summer, to carry over the IEP until school starts again.

ESP is funded through community donations, and holds fundraisers throughout the year, sponsored by local businesses, churches, and major corporations.

The best thing about ESP is actually feeling good about dropping my child off for the day. I have total confidence that he is safe, loved, and having a great time. What more could any parent ask? **EP**



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Circle #43

UNITED CEREBRAL PALSY (UCP)

Understanding Disabilities
Creating Opportunities

s the tenth anniversary of the passage of the Americans with Disabilities Act approaches and the world begins life in the twenty-first century, now is a good time to reflect on the powerful, positive changes that have occurred in the world of disability. These fundamental changes and advances in such areas as technology, barrier-free architecture, employment, and education have contributed to the goal of full inclusion of children and adults with disabilities in all aspects of the community. Over the years, one organization that has been a tireless advocate, innovative service provider, and powerful visionary in their quest to fulfill their mission of advancing the independence, productivity, and full citizenship of people with disabilities is the United Cerebral Palsy (UCP).

A proud history

The group was founded in 1949, when a group of parents of children with cerebral palsy banded together in New York City to find ways to provide a better life for their children.

This small group of parents, headed by Leonard Goldenson, founder of the American Broadcasting Company, and his wife, Isabelle, Jack Hausman and his wife, Ethel, and Nina Eaton, has grown into a powerful national organization. Today, UCP is a nationwide network of more than 140 state and local voluntary agencies (UCP affiliates) which provides programs and services and conducts public and professional education programs relevant to children and adults with cerebral palsy and other disabilities. "We started out just wanting a better life and chance for our children. It is amazing to see how far our effort has come. In those days, we were the only voice for our children and it is incredible now to see children with disabilities develop their own voice" says Nina Eaton, UCP co-founder and current national board member.

What UCP can do

Direct services provided by UCP affiliates include:

- physical and occupational therapy;
- assistive technology;
- information and referral;
- early intervention;
- employment skills training;
- individual and family support;
- social and recreation programs;
- community inclusion and independent living;
- advocacy and community education.

These programs and services support people with disabilities as they strive to reach their full potential and become full, productive members in their local communities.

Looking ahead

In April, UCP began a year-long, fiftieth anniversary commemoration which celebrates the rich history of the organization with an eye toward further growth and success in the future. As part of UCP's "eye toward the future," the organization is preparing for the launch of a new and dynamic public education campaign featuring a new Web site as well as radio, print, and television advertising which captures the essence of the agency's commitment to people first.

An integral component of the new public education campaign is the debut of a new, contemporary UCP logo (which appears on this page) and tagline "Understanding Disabilities, Creating Opportunities." This universal tagline and theme resonates throughout UCP as an organization, and especially with the people and families they serve. "UCP is about making a difference in the lives of children and adults with disabilities with cutting-edge, innovative programs one person at a time," says UCP National Volunteer President, Charles Moses III, Esq.

UCP on the Web

The innovative programs at the local level are only a small sampling of what is happening at UCP. In an effort to provide the latest information on a wide variety of happenings in the disability field, from new medical therapies, to important legislative information, to activities in each state, UCP has built a new, fully accessible

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> **"UCP is about making a difference in the lives of children and adults with disabilities with cutting-edge, innovative programs, one person at a time."**

continued from page 53

comprehensive Internet Web site.

This Web site provides information on national issues important to the disability community, as well as information and connections to local UCP affiliates across the nation. This new format allows every Web visitor the chance to find out the programs and services available in their local area, how to become involved in the program, as well as how to help the affiliate make a difference. "We are committed to being the preeminent information source for and about the disability community, and the Web gives us another important resource tool to fulfill that commitment" states UCP National Executive Director Kirsten A. Nyrop.

UCP has prided itself on two decades of sponsorship relationships with major corporations such as Tosco Circle K, Miller Brewing Company, Health South and TCBY. UCP was pleased to announce this year two new corporate sponsors—First USA and QVC. UCP will launch its own affinity card program first quarter 2000. Also, first time shoppers who shop on QVC and mention "UCP sent me" will drive additional revenue back into UCP. This is an exciting time for UCP. **EP**

To learn more about UCP, visit their Web site at http://www.ucp.org, or call (800) 872-5827.

Serving over one million Americans a year with cerebral palsy and other disabilities, UCP is the largest non-profit healthcare organization in the United States. UCP is also one of America's most financially responsible charities, with 85 percent of revenues being devoted to programs and services for individuals and their families through affiliates in 40 states.

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Circle #24

ROLE MODELS

The Best Offense is a Good Defense

Jay Leeuwenburg, speaks to children about coping with diabetes. He hopes that his positive message reaches children and young adults and motivates them to live life to the fullest.

by Kerry Pianoforte

n football, offensive linemen form the "brick wall" that protects the quarterback from the onslaught of the opposing team's defense. On the playing field, Jay Leeuwenburg, the 6'3", 290 lb. offensive lineman for the Cincinnati Bengals, stands his ground. Off the field, Jay Leeuwenburg does not let anything, especially his diabetes, stand in the way of his dreams. Jay was diagnosed at the age of 12 with Type 1, or "juvenile," diabetes. This lifelong condition, which affects more than one million Americans, can occur at any age, but is most commonly diagnosed in childhood. In Type 1 diabetes, the pancreas produces little or no life-sustaining insulin. People with this condition must take several insulin injections a day for the rest of the their lives. Before being diagnosed with juvenile diabetes, Jay had some of the classic symptoms such as an unquenchable thirst, frequent urination, and lethargy. The diagnosis was a shock for Jay and his family because there was no family history of the disease. He felt relief, however, upon receiving a diagnosis and proper treatment. He recalls, "I think I felt so bad from having been undiagnosed that as soon as I got my first shot of insulin I felt so much better."

[illegible]

Jay credits his parent's approach to his illness with helping him enjoy a happy childhood. "They did a great job of making ours a 'diabetic' family." Jay explains that as a family they all kept to the carefully balanced diet that he required to help keep his disease under control. "I have an older brother and never did I feel that because I have diabetes I missed out on something." Jay feels that this "team" approach to diabetes is important because, "children hate to feel different, they hate to feel alienated, and it is important to make them feel like they are still as normal as possible. People have to realize, particularly as a child, if you are going to a birthday party you're going to have cake and ice cream because it is important for you to fit in. You have to compensate by having less pizza, and you may have to take more insulin." This team approach is something Jay still practices at his home with wife Ingher and their two young daughters. "If I know that I'm going out and having dessert, I'll take some more insulin. As long as you have a little forethought and you actually think about what you're doing rather than doing whatever you want, you can reach a balance. I don't think it's dependent on whether you're diabetic or not, I think it's fairly good practice for everyone."

[illegible]

Throughout his life, Jay has defied the odds with his "can do" attitude. Jay would not allow diabetes to slow him down. "I always knew that I wanted to be active. Sports was a priority in my life, even as a child." Jay stresses that parents should encourage their children to pursue any activity, regardless of a disability. The NFL lineman believes that parents can help by eliminating

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ROLE MODELS

Getting "Pumped"

A new singing group called the Pump Girls is getting audiences "pumped" all over the country. The pop music group consists of four girls ages 12-15. The Pump Girls are Sarah Ann, 12 (their newest member not pictured), (counter clockwise) Brittany Rausch, 13, Colleen Cottrell, 14, and Sara Cronstedt, 15. These southern California girls sing about average teenage interests such as parents, boys, and dancing. But they also sing about some not-so-typical topics such as overcoming challenges and dealing with a life-altering condition. All of the girls in this group have Type 1 diabetes, and instead of taking insulin injections, they have been controlling their diabetes with an insulin pump, hence their name. (see box).

The group was started three years ago while the girls were on a family retreat, sponsored by PADRE (Pediatric Adolescent Diabetes Research and Education Foundation), which provides a wide range of services for children with diabetes including support groups and education. Brittany's mother, Corrie, was in charge of activities for the young girls. Corrie recalls, "Brittany and I thought it would be fun to do a skit and she had just gotten her pump. So we came up with the Pump Girls. We wrote the music and did it as a skit. It turned out that the company that makes the pump loved the idea and wanted to hear the song." This girl group that was put together by chance went on to produce an entire CD. The girls now spend one day a week rehearsing and keep themselves busy performing almost every other weekend.

The girls credit their insulin pumps with giving them more control over their disease and allowing them to become more active. According to Sara, "I feel better. A lot of time when you have high blood sugar you don't feel too good. You go from the highs and the lows and the peaks and the valleys, and you don't feel like yourself. I know that when I got my pump, I really started to have good control. I started to have more energy. It was an overall improvement in lifestyle."

In addition to singing and dancing with The Pump Girls, these young ladies lead very active lives. Colleen reports that she is constantly singing both in the group and in choir. Brittany is involved in soccer and Sara tutors elementary school children once a week.

Colleen advises other children and adolescents with disabilities to "keep a positive attitude and keep reminding yourself if you are willing to work at it you can control your disease and it doesn't have to control you. That's the kind of message we like to send out, that there's hope out there, that you can take control." Sara adds that one of the goals of the group is "to let as many people as possible know who we are and what we are about. We have such an important message. So many people deal with diabetes and if they don't deal with it personally, they know someone who does. So many people are affected by diabetes and a lot of people don't know that much about it. So basically our goal is to get our message out in a fun way. Although we deal with something that is out of the ordinary, we can still live life and live it to the fullest."

When helping children to be responsible for their healthcare, Brittany's mother, Corrie states that education is the most important thing. "The attitude the parent has makes all the difference in their child's. If they hate diabetes then their child is going to hate diabetes. If they are positive about it then their kids will be positive about it." She recalls when Brittany was 2 years old and had to take the usual diabetic blood test to check her blood sugar level. "We called it finger time and we made it a game and she looked forward to it." Corrie emphasizes the need for children to learn to control the disease themselves. "Parents walk a fine line between letting their children learn the importance of good control and all the while being in the background to help."

For now these girls show no signs of slowing down. They plan on continuing with their touring, making stops at children's hospitals, diabetes care centers, and schools where they can sing and get their message of hope out there.

For more information about The Pump Girls, visit their Web site at http://www.pumpgirls.com. For more information about the PADRE Foundation, call (714) 532-8330, or go to their Web site at http://www.padrefoundation.com.

The insulin pump, manufactured by MiniMed®, is a small programmable device, also known as a Continuous Subcutaneous Insulin Infusion or CSII, holds a supply of insulin and can be programmed by the user. As big as a pager, the pump is battery operated to send insulin into the body through a thin plastic tube called an infusion set. The infusion set contains a small flexible tube, called a canula that is inserted under the skin, and can be left in place for up to three days. The pump is worn outside the body, usually in a pouch or on a belt.

THE PUMP DELIVERS INSULIN IN TWO DIFFERENT WAYS:

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- **Bolus: a larger amount of insulin delivered over a short period of time.**

For more information on the insulin pump contact MiniMed at (800) 933-3322 or visit their Web site at http://www.minimed.com.

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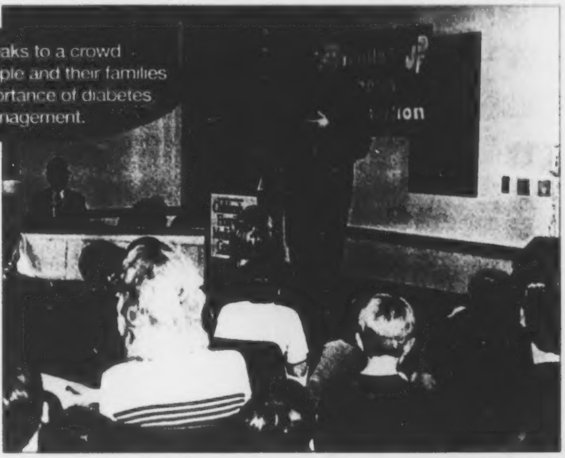
any fear of the unknown on the part of others. "The key to a successful experience, whether it be in sports or in the marching band, is education. Educate the coach or leader on the signs of the illness and then explain how it is treated. This avoids any fear of the unknown." Jay and his parents took this up-front approach and explained his illness to his coaches and teammates from the beginning. Even now, in the NFL, he is always willing to answer questions concerning diabetes.

After coming to terms with diabetes and understanding its treatment, Jay played football in high school, where he was a starting member of the football team. His football career continued at the University of Colorado, where he was selected as one of only four athletes in the university's athletic history to be nominated as a unanimous All American. Jay started his NFL career first with the Chicago Bears, followed by the Indianapolis Colts, and he is now with the Cincinnati Bengals.



Jay speaks to a crowd of young people and their families on the importance of diabetes management.

Jay is actively involved in the Juvenile Diabetes Foundation. He spends much of his free time speaking to children about the importance of taking care of oneself when you have this disease. Jay advises that children should not feel limited because of their disease, and parents should not fear letting their children try new things. Jays feels that "any individual who has diabetes can do whatever the or she wants, but they have to take some important steps. It's different for every individual with diabetes, but there are some universals like checking your sugars, being on a diet, getting exercise, and taking your insulin."

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Berkshire Meadows

Nestled in the serene beauty of Western Massachusetts' Berkshire Hills, Berkshire Meadows offers a comprehensive, integrated year-round residential program for children, adolescents and young adults who are severely developmentally delayed and may be multiply disabled.

We help our population become more independent, more self-sufficient and empowered. For their families we strive to offer education, encouragement, and support. We believe that all people, no matter how severe their disabilities, should be given the opportunity to achieve their maximum potential.

Berkshire Meadows
Gail Charpentier, Exec. Dir.
249 North Plain Road
Housatonic, MA 01236
(413) 528-2523, Ext. 14
berkshiremeadows.org

Circle #21

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Jay is able to maintain a physically rigorous schedule by constantly monitoring his blood sugar. Using his blood glucose monitor, he checks his sugar eight to ten times a day on a non-game day and even more frequently on a game day. This allows Jay to have tighter control over his disease by adjusting his insulin according to his blood sugar for that day. He also suggests that individuals develop a system tailored to their needs by talking to their doctor or diabetes educator.

One of the reasons that Jay Leeuwenburg has dedicated himself to being a role model for children is because he did not know of any people who had diabetes that he could look up to when he was a child. He hopes that children will see the example that he sets and realize that people with diabetes can do anything they set their minds to. Jay cannot stress enough how important it is to take insulin shots. "The way I think of it now is that insulin is just life support until they find a cure."

Jay has hope that someday in the near future there will be a cure for this disease. With his work with the Juvenile Diabetes Foundation he hopes to raise awareness and educate young people on maintaining their health. Jay advises that people stay informed about the latest advances in diabetes research. "I like to stick with what works, but I found out there are better ways that I can be monitoring and living my life with diabetes. There's new technology, new insulins, and meters."

Jay has no plans of slowing down. Right now he is busy balancing the demands of family life, being an NFL player, and his obligations as a spokesperson for the Juvenile Diabetes Foundation. Jay wants parents and children alike to understand that diabetes does not have to limit you. Parents need to educate themselves to better understand the disease. Children need to know that with proper healthcare, they can lead active, healthy lives. As Jay would say "You need to control your diabetes, not let your diabetes control you." This sound, offensive strategy will control any defense, and any disability. **EP**

For more information on Type 1, juvenile diabetes contact:
The Juvenile Diabetes Foundation
120 Wall Street, 19th floor
New York, NY 10005-4001
Phone: (800) 533-2873
Fax: (212) 785-9595
Web site: http://www.jdf.org

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Circle #70

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Music Therapy
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Adapted Recreational Activities

Computer Technology
Communication Devices
Environmental Control
Powered Mobility

HMS, founded in 1882, is open to students two to 21 years. The experienced staff and well-respected consultants provide strong interdisciplinary programs for day and residential students at the licensed private school.

For more information write or call:
Diane L. Gallagher, Ph.D., Director

HMS School
For Children With Cerebral Palsy
4400 Baltimore Ave, Philadelphia, PA 19104
(215)222-2566

Circle #44

Beyond Access:
UNIVERSAL DESIGN FOR LEARNING™

by Anne Meyer, EdD, and Lucinda M. O'Neill

The ultimate goal of any student is to learn. However, having access to information is not the only essential ingredient in achieving that goal.

Education requires challenge and resistance. A balance must be found that allows maximum access (which requires reducing or eliminating resistance) and maximum learning (which requires meeting or overcoming resistance). Universal Design for Learning™ (UDL) is the paradigm developed by the Center for Applied Special Technology (CAST) for teaching, learning, and the development, selection and use of curriculum materials. Universal Design provides the challenge and resistance—requiring careful attention to the goals of any given learning experience when selecting curriculum materials and deciding what modifications are appropriate.

Universal Design in practice

If the goal of a teacher is to teach word decoding to a student with a learning disability, for example, having the computer read all of the words aloud could undermine learning. On the other hand, if the goal is to convey science concepts, having the computer read the text aloud could enhance the learning opportunity for the same student.

Each student, with or without a disability, is unique. Categorical approaches that label students, such as "disabled," "average," or "gifted," make broad assumptions about the similarities of students within categories while missing the differences. They also make assumptions about the differences among students across categories while missing the similarities.

Youngsters gathered around a computer at the CAST Center in Peabody, MA. CAST has put into practice their concept of learning through full access balanced with challenge.

Universal Design for Learning, as conceptualized by CAST, shifts old assumptions in key ways. First, students with disabilities fall along a continuum of differences as learners rather than constituting a separate category. Second, adjustments for differences in learning occur for all students, not just those with disabilities. Third, universally designed curriculum

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materials are varied and diverse, including digital and online resources, rather than centered on single textbooks. Ultimately, instead of "fixing" students so that they can manage a set curriculum, UDL "fixes" the curriculum by making it adjustable.

The concept of UDL evolved from the simultaneous emergence of new knowledge about the brain and new technologies for learning and communication. Neuro-imaging techniques have enabled researchers to better understand the neurological basis for differences in learning. At the same time, networked multimedia tools and content are now supporting the creation of flexible curricula in ways that were never before possible.

The "universal design" concept has its roots in architecture and product design, where physical access is the goal. Architects practicing universal design create structures that are dedicated to accommodating the widest spectrum of users, including those with disabilities. In universally designed environments, adaptability is subtle and integrated into the design. A distinct benefit of universal design is that designing for the divergent needs of "special" populations increases usability for everyone. The classic example is the curb cut. Originally designed so that people in wheelchairs could negotiate curbs, curb cuts also ease travel for people pushing carriages or riding skateboards, pedestrians with canes, and the average walker. Similarly, the widespread use of captioning on television has been a boon to exercisers, customers in noisy bars, individuals working on their language skills, and roommates who go to sleep at different times.

A DISTINCT BENEFIT OF UNIVERSAL DESIGN IS THAT DESIGNING FOR THE DIVERGENT NEEDS OF "SPECIAL" POPULATIONS INCREASES USABILITY FOR EVERYONE.

Flexibility allows access

Universal Design for Learning extends the concept of universal design in two ways: 1) it applies the idea of built-in flexibility to curricular materials, and 2) it requires that teachers use these flexible materials to provide more than "access" to help students learn.

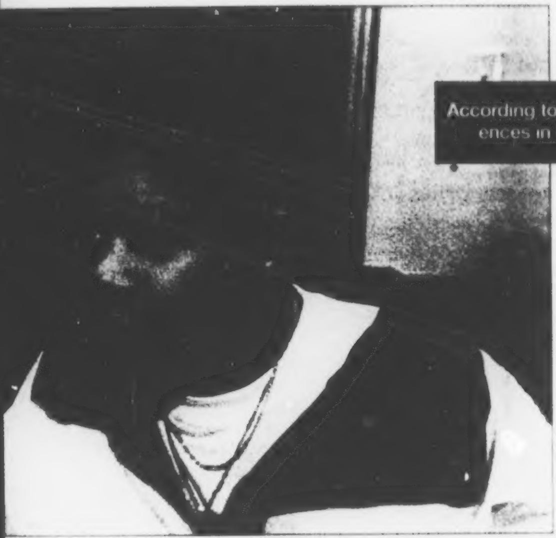
Because the key to UDL is individualization, the key characteristic of UDL materials is flexibility. Although individualization is theoretically possible with traditional materials such as textbooks, UDL is predicated on the flexibility of digital media and tools, including digital content, adjustable technology tools for accessing and operating on that content, and networked resources such as the World Wide Web. Non-digital materials tend to be

individual, self-contained units ("a" book, "a" video tape) and are largely inflexible—what comes out of the box is what you get, with essentially no viable means of modifying it. Teachers wishing to practice UDL with these traditional materials would confront virtually insurmountable problems. They would need large, costly collections of physical materials so that choices would be available for different students.

Electronic ease

Digital media, on the other hand, can be designed to be highly flexible because of their capacity to be transformed. Unlike a printed book—which has fixed, unchangeable text and images, but no sound, animation, or video–the digital environment (e.g., computers) can carry any and all media simultaneously. Text-to-speech or speech-to-text via speech recognition software can be programmed into online tools and software so that the transformation from one medium to another can take place for users who need the alternative medium. For example, if a student with dyslexia needs a particular word read aloud, the computer will read it "on demand." Image and video descriptions in digital speech provide access to those who cannot see the images. Captioning of dialogue, music, or sound effects, accomplished with a combination of text and graphics on screen, provides access to those who cannot hear the sound.

Text-to-speech and captioning are access features that become "smart" when they are designed with the instructional purpose in mind. The next generation of CAST software tools will go further, offering built-in teaching supports that make these products truly universally designed for learning. The current version of the CAST eReader™ offers text-to-speech and highlighting supports that help students with disabilities access information on the World Wide Web; the next version will help students develop Web-searching strategies



According to CAST, access to curriculum benefits all students because differences in learning occur for all students, not just those with disabilities.

to maximize their use of the Web for learning. Another tool under development at CAST will work with digitized textbooks to help students with learning disabilities develop the organizational skills that are critical to their success in school.

Although technology is at the heart of both UDL and assistive technology, it is important to clarify the differences. Assistive technology is designed to help individual students access the mainstream curriculum. Under most circumstances, assistive technology is necessary because the mainstream curriculum is inflexible and inaccessible to those students without it. For example, a video enlarger can make a textbook more accessible to a student who has low vision. But the enlarger is not a part of the curriculum, it is a device used by an individual student to overcome a barrier inherent in the curriculum's original design.

Assistive technologies can allow the learner to adapt to the curriculum. This way, there is access and the challenge is one that stimulates learning rather than hindering it. Rather than requiring a video enlarger to make 12-point black-on-white text legible to a student with a visual impairment, a UDL curriculum would include a digital version of the text that could easily be enlarged to the necessary size and changed in color if necessary. Once digitized, that text could be converted to speech and "read aloud" for students with difficulty decoding words. It could then be copied and pasted into a "concept mapping" software program for students with organizational difficulties. It can also be saved into an on-screen "notepad" which manages text for a student preparing to write an essay. The built-in flexibility eliminates the need for the assistive tool, and simultaneously improves learning opportunities for all students.

A student learns to use one of the software tools developed by CAST which allows access to class work material.

The full implementation of UDL may reduce but not eliminate the need for assistive technologies. As Universal Design for Learning becomes viable and pervasive, the power of assistive technology can be devoted to providing more efficient interaction with a curriculum that is already access-aware. For the students who need it, assistive technology will no longer be required to overcome barriers in a poorly designed curriculum, but it will enhance active interaction with a curriculum that has been designed at the outset to be accessible to all. **EP**

Since 1989, CAST has been engaged in the research and development of software products, Internet tools, and model educational programs that go beyond access to support learning. Universal Design for Learning™: Mind, Media and Instructional Design, a forthcoming book by Co-Executive Directors Anne Meyer, EdD, David Rose, EdD, and staff members of CAST, will explore issues discussed in this article in depth.

Anne Meyer, EdD, is co-executive director of CAST, the not-for-profit Center for Applied Special Technology, in Peabody, Mass. Lucinda M. O'Neill is a staff writer at CAST.

THE BUILT-IN FLEXIBILITY ELIMINATES THE NEED FOR THE ASSISTIVE TOOL, AND SIMULTANEOUSLY IMPROVES LEARNING OPPORTUNITIES FOR ALL STUDENTS.

WHAT'S HAPPENING

Beginning this month, What's Happening will include a new consumer product recall section. Each month we will publish information on a product that has been recalled. This information is obtained from the U.S. Consumer Product Safety Commission. For more information on product recalls, call (800) 638-CPSC or visit their Web site: http://www.cpsc.gov.

U.S. Consumer Product Safety Commission product recall information

In cooperation with the U.S. Consumer Product Safety Commission (CPSC) and the National Highway Traffic Safety Administration (NHTSA), Kolcraft Enterprises of Chicago, IL is recalling about 754,000 infant car seat/carriers for repair. When used as an infant carrier, the handle can unexpectedly move. When this happens, the infant can fall to the ground. Kolcraft is offering a free repair kit to address this problem. The Kolcraft infant car seat/carriers models to be recalled are: Infant Rider, Secura, Travel-About, Plus 4, Kolcraft Infant Restraint, Kolcraft Infant Car Seat and Playskool Infant Car Seat, all manufactured between January 1, 1993, and June 30, 1999. The five-digit model/style number and manufacture date, written as month/day/year, and possibly the model name are written on a label on the side of the seat. Some car seat/carriers were also sold with strollers. If the first digits of the model/style numbers on your car seat/carrier match the numbers in the following list, then it is subject to this recall: 1212X, 1382X, 1383X, 1384X, 1385X, 369XX, 43XXX, and 7700X. There are a total of 50 model/style numbers affected by this recall. To receive a free repair kit, call Kolcraft at (877) 776-2609.

New catalog of brain injury prevention materials available

HDI Publishers, in conjunction with the Brain Injury Association (BIA) and the Violence and Brain Injury Institute (VBII), has created a comprehensive list of brain injury prevention resources for teachers, parents, rehabilitation professionals, nurses, and others who have an interest in brain injuries. *Prevention & Educational Tools for Brain Injury* contains over 30 materials designed to help people understand more about brain injury—how it occurs, what happens when brain injury strikes, and what can be done to prevent it. Also included in the catalog are posters, folders, pencils, and coloring books for school-age children, as well as implementation manuals, calendars, and public service announcements for people working with children. For information on how to receive a copy of this publication, please contact Chas Haynes at (800) 321-7037 or E-mail: chaynes@hdipub.com. Information on brain injury can also be obtained from the Brain Injury Association's Web site at http://www. biausa.org.

Autism awareness rally in Washington, D.C.

On April 8, 2000, the Autism Resource Konnection (ARK), Inc., will be hosting a National Autism Awareness Rally in Washington, D.C. There will be information booths, professional and parent speakers, and a continuous slide show of people who have autism. "Unlocking Autism" will display a pictorial tribute of children affected by autism. For more information on submitting a photo, please call (225) 769-1532, or visit their Web site at http://www.littleangels.org. The first

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CALENDAR OF EVENTS

APRIL
5-7

Human Services Consultants Management, Inc.

WOODLANDS INN AND RESORT, WILKES-BARRE, PA

Topics will include legal issues, applied behavioral analysis, and language development. For more information call (888) 879-8858; Web site: http://www.hscm.com.

APRIL
6-8

Building on Family Strengths: a national conference on research and services in support of children and their families.

HILTON PORTLAND, PORTLAND, OR

There will be paper and panel presentations related to improving services for families whose children and adolescents have emotional, behavioral, and mental disorders. For more information call (503) 725-8118; fax: (503) 725-4180; E-mail: elizabr@rri.pdx.edu.

APRIL
14-16

Abilities Expo New Jersey Convention Center.

NEW JERSEY CONVENTION CENTER, EDISON, NJ

Attendees will learn about the latest in assistive living products and services, as well as answers to important questions concerning insurance coverage, government regulations, and available services. For information call (800) 382-3085, Web site: http://www.abilitiesexpo.com.

APRIL
15-17

Developmental Disabilities Nurses Association Eighth Annual Education Conference

SHERATON HOTEL AND CONFERENCE CENTER, BURLINGTON, VT

This conference is for any professional interested or involved in the care of people who have developmental disabilities. Topics will include epilepsy, dental care of people with developmental disabilities, social skills, and basic genetics of people with developmental disabilities. For more information call (800) 888-6733; fax: (541) 485-7372.

APRIL
16-19

NISH 2000 National Training Conference

THE CRYSTAL GATEWAY MARRIOTT, WASHINGTON, D.C.

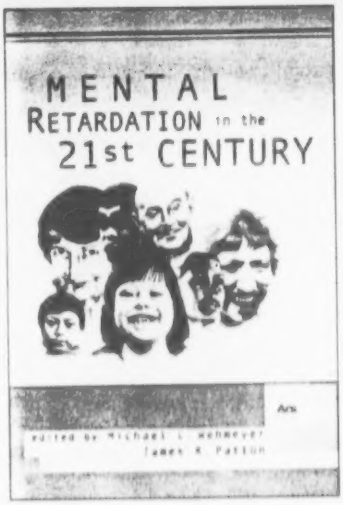
For more information call Lisa Ward, Director of Corporate Communications, at (703) 641-2757; 2235 Cedar Lane, Vienna, VA 22182. NISH is a nonprofit organization mandated by Congress to assist Community Rehabilitation Programs employing people with severe disabilities to obtain federal contracts under the Javits-Wagner-O'Day (JWOD) Act.

BOOK NOTES

Mental Retardation in the 21st Century

EDITED BY MICHAEL L. WEHMEYER AND JAMES R. PATTON

Published: 2000 PRO-ED, Inc. 457 pages
Available through the EP Library: (800) 535-1910: code PE181MR
Cost: $42.00 plus shipping and handling
Royalties from this book go to the Arc.



Mental Retardation in the 21st Century deals extensively with self-determination and self-advocacy for people with mental retardation, and examines the ways in which the concept of quality of life has evolved over the past two decades, and the direction it is taking for the future. Divided into seven sections, the book takes a look at all areas of life, from early childhood through adulthood, beginning with Family, and moving on to Education, Employment and Residential Issues, Psychology, Medicine and Health, Life-Span, and Policy.

Each section contains chapters written by various authors, including parents, advocates, and educators. The book contains both an author and subject index, and references at the end of each chapter. Chapters deal extensively with self-determination and self-advocacy, and examine the ways in which the concept of quality of life has evolved over the past two decades, and the direction it is taking for the future. The last section deals with policy issues, including service delivery systems and the social constructions of mental retardation during the last century. Social constructions are the ways in which the meaning of mental retardation has been shaped and changed, and the fact that these meanings have usually been the result of a search for social control rather than concern for the individual. It mentions various attitudes that were accepted in the past and suggests the need for a new definition, or even a new term for mental retardation, and the impact these changes could have on society.

In Chapter 16, "Toward a Brighter Future for Persons with Down Syndrome," the author, Siegfried M. Pueschel, MD, PhD, JD, MPH, of the Child Development Center at Rhode Island Hospital, writes first of the historical perspective in which Down syndrome has been considered. Immediately following this is a section titled "Accomplishments during the past decade." This passage highlights medical research in the field which may lead to improvements in care, including counseling of parents, addressing gastrointestinal anomalies, heart disease, cataracts, nutrition, early intervention, dental care, and many other concerns for children with Down syndrome. Pueschel then moves on to discuss education, of which he says, "When children with Down syndrome enter school, we often wonder what they will get out of their educational experience. We hope that school will provide the kind of stimulating and enriching experiences that make the world appear to be an interesting place to explore. Learning situations should provide children with Down syndrome a feeling of personal identity, self-respect, and enjoyment." He continues, "Through effective planning, development of appropriate support, and a shared commitment, post secondary educational programs can provide people with Down syndrome opportunities to pursue their dreams and goals." The chapter addresses meaningful employment, living options, and relationships. In his conclusion Pueschel writes, "Beyond the myriad of future research possibilities…many more investigations need to be carried out to increase the knowledge in this field which, in turn, will improve the quality of life for persons with Down syndrome."

Chapter 18, "Riding the Third Wave: Self-Determination and Self-Advocacy in the 21st Century," by Michael L. Wehmeyer, PhD, Hank Bersani, Jr., PhD, and Raymond Gagne, deals with the self-advocacy movement, and the course it is taking. The first section of the chapter is entitled "Powerless Lives," and details the stereotyping that accompanied mental retardation throughout the 20th century. Included is the story of Raymond Gagne, who is now a leader in self advocacy and self-determination. He was born in 1945 with cerebral palsy. He writes of his childhood in an institution, where he was treated with inhuman cruelty. When he reached adulthood, he left the institution, became involved in self-advocacy and now leads a fulfilling, independent life.

The authors write that, "Many self-advocates actively campaign against congregate settings, such as nursing homes and advocate for social justice…In addition, self-advocacy groups have become a training ground for leaders, enabling people with mental retardation to assume leadership positions. Self-advocates now sit on visible boards and committees, including the board of directors for organizations like the Arc, the American Association on Mental Retardation, and TASH as well as serving on the President's Council on Mental Retardation and the President's Committee on the Employment of Persons with Disabilities."

Gunnar Dybwad, PhD, concludes the book with his "Epilogue," paying tribute to the energy of the parent movement: "It is indeed regrettable that the far-reaching effectiveness of the parent movement, just now celebrating 50 years of successful advocacy, has not been given the attention it deserves in much of the professional literature. As professionals, and friends of people who experience intellectual disabilities, we must never overlook the far-reaching effectiveness of the parent movement…Today, advocacy organizations across the globe advocate for and with people with intellectual impairments in uniform agreement of the importance of community inclusion for all." Dr. Dybwad writes about how past atrocities against people with mental retardation in institutions must not be forgotten, and calls on professionals to acknowledge their role in the situation.

Excerpts reprinted with permission from PRO-ED, Inc.

WHAT'S HAPPENING

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ever Autism Awareness Quilt, will be on display. If you would like to submit a quilt patch call (281) 256-3034 or visit their Web site at http:// www.iquonline.net/ark/acalltoaction.htm. For information, or to volunteer in ARK's efforts, call (877) NO AUTISM or visit their Web site at http://www.ark-inc.org.

Online support groups

Two online support groups for families with members affected with Laurence Moon Beidl syndrome (LMBS) and retinitis pigmentosa (RP) are now available. Contact Sue McCoy via e-mail at mmandm@ozramp.net.au.

Free consumer information catalog

The Consumer Information Catalog Winter 1999-2000 is now available. This free catalog is filled with more than 200 free and low-cost government publications that include tips on saving money, eating right, taking care of children, and travel safety. Some of the publications include the Consumers Resource Handbook; 66 Ways to Save Money; and Social Security: Understanding the Benefits. To obtain a copy of this catalog by phone, call (888) 878-3256; by mail: Consumer Information Catalog, Pueblo, CO 81009; or via e-mail at http://www.pueblo.gsa.gov.

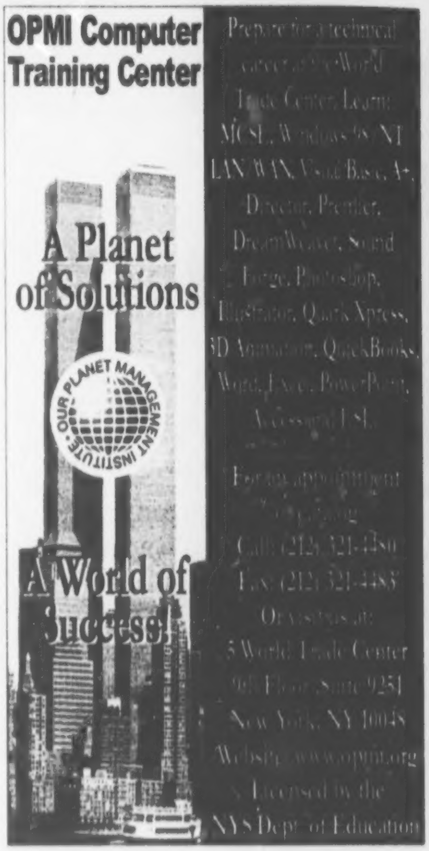
Resource Guide 2000 Corrections

The "Alliance for Technology Access Centers" directory contained an outdated toll-free number for the Michigan Assistive Technology Resource. The correct number is (800) 274-7426.

In the "National Resources for Specific Disabilities" directory The Organic Acidemia Association's address is incorrect. The new address is 13210 35th Ave. North, Plymouth, MN 55441.

There is a new telephone number for the the Association of Children with Down syndrome. The number is (516) 933-4700.

We regret these errors.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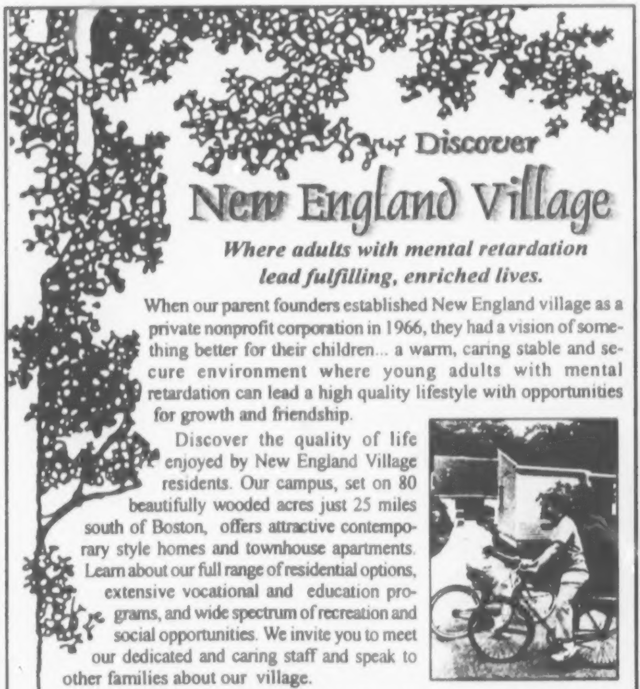
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PERINATAL

MEET THE PERINATOLOGIST:

An Introduction to This Specialist's Role in Caring for Your Child

by John Joseph Botti, MD

An obstetrician, primary care physician, or midwife can handle most routine pregnancies. When complications are anticipated because of the mother's medical history, or if they crop up during the pregnancy and threaten to affect the health of the fetus or mother, a specialist may be required. The perinatologist, a specialist in maternal-fetal health, is the person who often receives these referrals. The referrals are frequently made when the mother's health provider wants her to receive care where there is a neonatal program.

In addition to basic obstetrics and gynecology training, the perinatologist has completed a two-year or three-year clinical and research fellowship. During this fellowship, he or she receives advanced training in comprehensive diagnostic ultrasound imaging of the fetus. These studies look for abnormalities in the head and neck anatomy, spine, heart, chest and diaphragm, stomach, kidneys and bladder, abdominal wall and umbilical cord, upper and lower extremities, the placenta, and the volume of amniotic fluid. These targeted ultrasounds are usually performed at about 18 to 20 weeks. Further studies may be recommended later in the pregnancy if there are problems that could affect the growth and development of the fetus, such as problems with the volume of amniotic fluid—or the function of the umbilical cord—that could affect blood flow.

Many perinatologists also develop diagnostic skills and can perform complicated procedures when serious fetal disorders are suspected. This may include sampling of the fluid surrounding the fetus (amniocentesis), obtaining blood samples from the umbilical cord, or placing catheters into the fetus.

The knowledge gained from these diagnostic procedures may contribute to therapeutic management and buy valuable time for the fetus until neonatologists (specialists in medicine of the newborn) can take over after delivery. Management of fetal health may also include administering medications across the placenta or amniotic fluid to correct a problem before birth.

In some cases, the perinatologist may be the best person to perform the delivery of a high-risk pregnancy, such as a multiple birth (twins, triplets, etc.). Perinatologists may plan and coordinate the delivery of mothers with medical problems, such as diabetes. They will also work with the neonatal care team to develop a plan for specialized care immediately after birth for babies who will need special management. The perinatologist may also consult with a genetic counselor if the need arises. For example, if the family has a history of diseases with a genetic basis, or the laboratory tests indicate a child is likely to be born with a genetic disease. The counselor can help them understand the actual meaning of the clinical diagnosis and its implications for the child's growth and development.

Perhaps the most significant contribution of the perinatologist is as a communicator. When given unsettling news about their baby, parents need information from a knowledgeable and caring doctor who can provide reassurance. The perinatologist can act as a sounding board for parental concerns, provide options for care, and act as a liaison between the referring doctor and the other members of the healthcare team who become involved after birth. Careful collaboration among perinatologists, neonatologists, and pediatric surgeons, or pediatric cardiologists, improves the prospects of a healthy outcome for an infant with special healthcare needs.

As advocates for both baby and mother, perinatologists are in a unique position to maximize perinatal health outcomes.

This series will continue with a description of the various specialists the parents and child will encounter in their efforts to promote the growth and development of the child. **EP**

John Joseph Botti, MD, is Professor of Obstetrics and Gynecology and Radiology at the Pennsylvania State Geisinger Health System, Hersey Medical Center, PA. He has spent more than 20 years as a specialist in maternal-fetal medicine, caring for high-risk women and families.

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FAMILIAR FACES

Ashley Azzardi (left), 5, and **Artie Conforti**, 1, enjoy playing together! Ashley has cerebral palsy and uses a powerchair. She started kindergarten last fall and loves it. Artie was born without his left hand. He uses a passive prosthesis and has adapted quite well. Artie receives occupational and physical therapy weekly. The two friends love Teletubbies and Rug Rats. Ice cream is also a favorite of both! Ashley lives in Uniontown, PA, with her mom, Kris, and dad, Anthony. Artie lives with his parents, Tina and Bill, in Greensburg, PA.

According to his "Grammy," Lena Lou Thomas, **Matthew Davis Gibson**, 6, brings joy to his whole family. Matthew suffered brain damage at birth and uses a wheelchair. He is nonverbal, but Lena says, "He is a bright child who likes letters, numbers, and music." His favorite activities are watching TV, being read to, and swimming. He enjoys attending Gateway Education Center in Greensboro, NC. Matthew lives in Jamestown, NC, with his parents, Jim and Jenny, and brother Sam, 4.

Allison Werne, 17, has cerebral palsy and uses a wheelchair. Her favorite activity is mowing the lawn, something she can do now that her dad engineered a special adaptive device. Allison will graduate from high school next year and is writing a book about her life. She lives with her parents, Terry and Gail, and her sisters Korrine, 20, and Katelyn, 13, in Huntingburg, IN.

Would you like to share a favorite candid snapshot or slide of your child and/or family with other readers of *EXCEPTIONAL PARENT*? Send it to: Readers' Photos, *EXCEPTIONAL PARENT*, 555 Kinderkamack Road, Oradell, NJ 07649-1517. (Please do not send originals or "one-of-a-kinds" as we regret that photos cannot be returned.)

Kristen Elizabeth McGuire, 3, poses for a portrait with her brother **Joel**, 6. Kristen has mitochondrial disease with multiple disabilities and central sleep apnea. She is nonverbal, nonambulatory, and has a feeding tube. Kristen attends a special preschool and enjoys it very much. She is fond of being rocked and talked to. She recently had water therapy for the first time--she loved it! Kristen and her brother live with their mom, Janelle, and dad, Mark, in Burlington, IA.

Chandler, 6 (left) and **Spencer Osborn**, 9, clown around! Both boys have lissencephaly (smooth brain), microcephaly (small head), profound mental retardation, seizure disorder, spasticity, and cortical blindness. They receive home-based occupational therapy twice a week and are cared for at home by a private nurse. Both boys love to snuggle and be held. They live in Boise, ID, with their parents, Doug and Shirley.

Big sister, **Laura Grassi**, 10, and **Carolyn**, 6, take time out for a picture. Laura has cerebral palsy and uses a walker. The fifth grader enjoys horseback riding, computers, drawing, and watching hockey on TV. The sisters also have a brother, Stephen, who is 9. Laura and her siblings live with their parents, Elizabeth and Sebastian, in Troy, MI.

***Now on the Web!** We will now be including Familiar Faces and Children's Page on our Web site, www.eparent.com. Please send us your photographs with the understanding that doing so gives Exceptional Parent permission to put the photos on the Exceptional Parent Web site, exactly as they appear in the magazine and with the same text.*

On a separate sheet of paper, write your child's full name, age at the time the photo was taken, address and daytime phone number. Please identify everyone in the photo. If you like, you can also write a few sentences about your child. Then look for a familiar face in an upcoming issue!

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Circle #27

ASK THE THERAPIST: Hip Stability and Learning to Stand

by Ginny Paleg, MS, PT

Q *Samuel is four years old. At five weeks of age he was the victim of severe child abuse. He was diagnosed with "shaken baby syndrome." Samuel came into our lives at the age of two months. We left the hospital with a beautiful baby who wasn't expected to live, would be tube fed, blind, deaf, have cerebral palsy, seizures and with no chance at ever having any independence. Since then, Samuel has made great strides, and we celebrate each one. He is a very happy healthy 42-pound boy. He is not tube fed; he is blind, but his hearing is very sharp. He has been seizure free for three years. Samuel has low tone and loves being around children, music, and school. Samuel's smile and giggle brightens the room.*

We are very concerned about his hips and we feel there is more to his life than sitting in a chair or lying on the floor. My dream is that Samuel can stand for transfers and maybe even learn to walk. How can we help him?

—B. H., Vinton, Virginia

A You are wise to be concerned about Samuel's hips. Hip dislocations and bone deformities can be the result of lying or sitting in one position for extended periods of time. It is not surprising, then, that hip displacements often begin early in the life of a child with severe disabilities. In many children, hip dysplasia (abnormal development of the hip joint) is the result of one group of muscles contracting more strongly than the opposing group of muscles. Bones grow and are formed based on the way muscles pull on them, so low or high muscle tone has an impact on bones.

Hips are particularly vulnerable to deformity. In many joints, the structure of the joint itself is what keeps the bones aligned. In the hip, muscles must align the bones. A child with low tone has very little muscle strength to keep the top of the femur (thigh bone) in alignment with the acetabulum (cup-shaped socket in the pelvis). With normal muscle activity and weight bearing, the pull from the muscles actually shapes the angle and orientation of these two bones. Without this pull or weight bearing, the joint can fail to form properly.

There are two separate issues to consider. The first one concerns hip stability. When a person is properly aligned in a stander, the head of the femur can be pushed into the hip socket as a result of stacked body weight. This pressure can deepen the socket and make the hip more stable.

Children who are not yet walking can benefit from standing with support. There are two basic types of standers. One gives support from behind the child (supine) and the other gives support from the front (prone). The direction of support does not make as much difference as the degree of incline of the person's body. If Samuel is reclined on a supine stander (even slightly), he will not need to actively use his muscles. If he is upright or leaning slightly forward, he will need to work at controlling his head and upper trunk. When he picks up his head, he will have a tendency to use leg muscles as well. The prone stander combines passive stretching while strengthening the upper trunk and promoting head control.

Standing for 45 minutes a day can also help to maintain bone density and slow the rate of development of osteoporosis. The other benefits of standing include improving respiration, circulation, digestion, and excretion.

Active standing

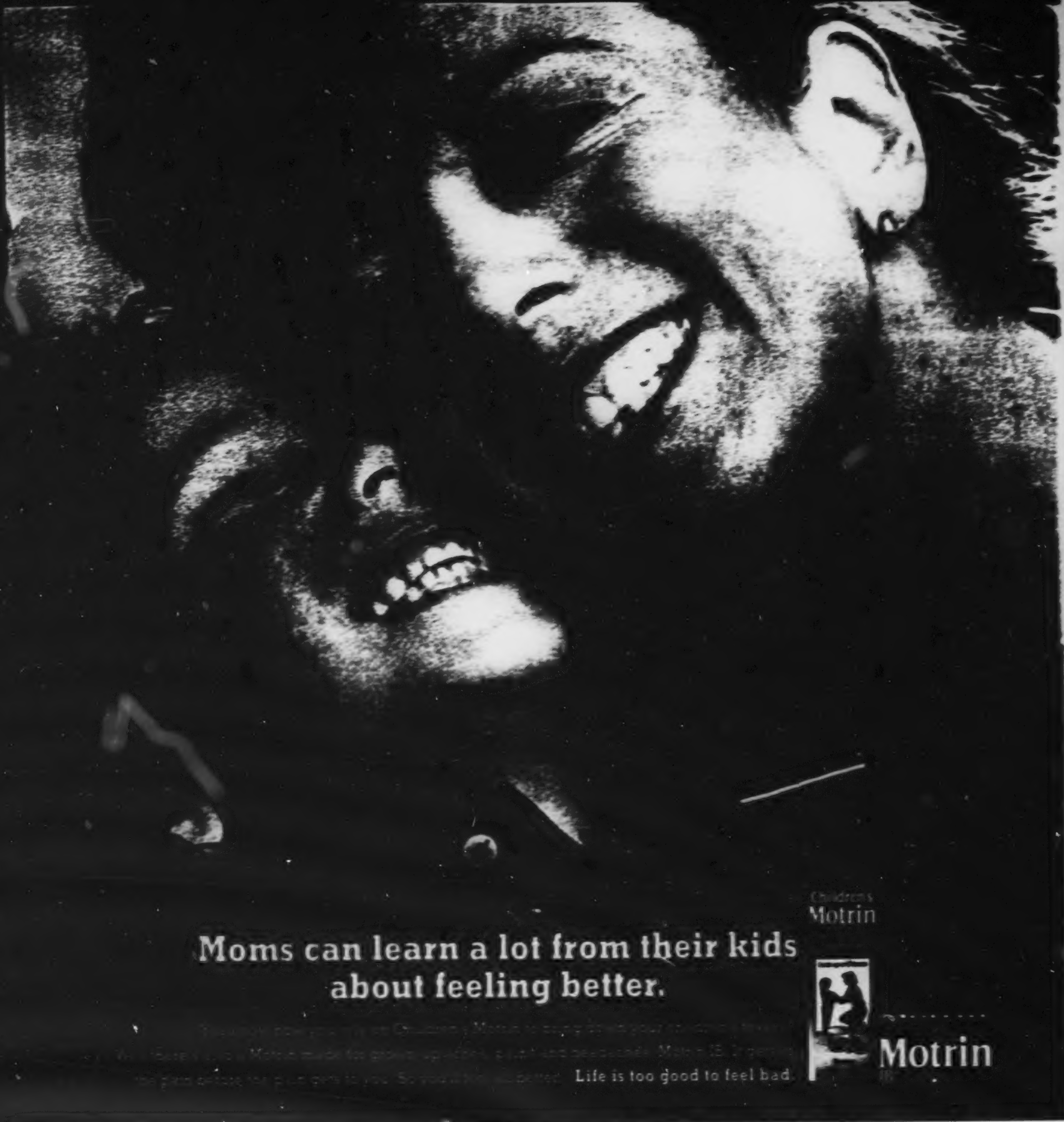
Traditional stationary standers do not help children learn to stand any more than sitting in a parked car helps a person learn to drive. Active participation is required if its purpose is to be served, so the second issue is learning to stand. Learning to stand without support requires the child to coordinate opposing muscle groups to keep the body from collapsing. This requires self-initiated muscle activity. From my experience, the most effective way to teach children to stand is to

continued on page 70

Ask the Doctor addresses issues of concern to our readers and is usually coordinated on a monthly basis by David Hirsch, M.D., a pediatrician and member of *Exceptional Parent's* Editorial Advisory Board. Dr. Hirsch is a partner in Phoenix Pediatrics, Ltd., in Phoenix, Arizona, and specializes in treating children who have developmental disabilities and chronic illnesses.

Parents should review any suggestions made in this column with the appropriate professionals. Mention of specific products or medications illustrate suggestions and are not endorsements of any specific products.

Send questions to: **Ask the Doctor,** *Exceptional Parent,* 555 Kinderkamack Road, Oradell, NJ 07649-1517, or fax, (201) 634-6570.



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continued from page 68

teach sit-to-stand transfers. Sometimes, holding children in a standing position and gently bouncing them on their feet helps to increase tone and activate muscles. Whenever possible, these skills should be incorporated into life activities rather than practiced in isolated sessions. Samuel's therapist can teach you ways to do this. For example, every time Samuel moves from one position to another, he should be encouraged to help push himself to standing and bear his weight for a few seconds. This assures that Samuel practices his skills in short sessions so he does not become fatigued, and the strain on you is reduced.

> Hip dislocations and bone deformities can be the result of lying or sitting for extended periods of time.

The newer standers are combined with large wheels that enable children to push themselves around their environment. The best ones allow variable hip extension as well as variable degrees of trunk support. As the child gets stronger, support can be decreased. When the child pushes the wheels, muscles throughout the body are activated. (See next month's issue of *Exceptional Parent* for a full report on self-propelled walkers.)

Another alternative is a gait trainer. These devices are similar to walkers but offer more support for the trunk, hips and arms. If used properly, gait trainers can help a person learn to stand and take steps. Many gait trainers can be adjusted to give maximal trunk support so that active weight bearing can be taught without another person having to support the weight of the child. Children can practice skills and strengthen muscles without requiring a burdensome amount of assistance from the adult.

Expectations

Doctors and therapists often tell families that their children will never walk. This is based on research conducted mostly in the 1970s. Today we know more about the brain and how it develops. Normally-developing children do not fully integrate and use the cerebellum (the part of the brain used for balance and coordination of muscles) until they reach 4 to 6 years of age. The frontal lobe (the part of the brain responsible for logic and reasoning) is not fully functional until puberty. I do not think we can really predict Samuel's potential.

No matter what the future holds, in order for Samuel to be as functional as possible and to make it easier for you to care for him as he grows, he should begin to learn to sit, stand, and walk now. Here are some suggestions for working toward your goals:

- At home and at school, he should sit upright in a correctly sized chair for short periods of time. If possible, he should be seated at the same height as his peers and in the same environment. He should have enough support to keep him safe, but he should be encouraged to move out of balance and then back into balance while sitting. This should be done during a classroom or home activity. An example of this activity is leaning and reaching to one side to get a toy.
- He should stand a minimum of 45 minutes a day. This can be accomplished in several sessions if he gets bored or seems uncomfortable.
- He should help assist in a pivot transfer each time he is moved. He should also be expected to help raise himself from a sitting to standing position.
- If possible, he should be encouraged to extend his own hips and knees to maintain his body weight for increasing periods of time as he grows stronger. Diaper changes can be done in this supported standing position.
- If a gait trainer is an option, he should be encouraged to stand and use his legs to move himself around.

Samuel is fortunate to have loving parents who are looking to his future. He needs the opportunity to learn, to practice these skills, and to understand the reasons for doing these things. Rather than setting up an "exercise program," he needs to use his skills within the flow of his real life. As he grows larger, he will be increasingly difficult to lift and move. He needs the dignity of bearing his own weight. He is far more like the rest of us than he is different. Good luck and keep up the good work. **EP**

In this column, Ginny Paleg, a pediatric physical therapist, answers questions from readers. Ginny works at The Hospital for Sick Children, in Washington, D.C. She specializes in treating children with developmental disabilities and neurological dysfunction.

Since Ginny has not assessed the child in question, parents need to review her suggestions with appropriate professionals. Mention of specific products, medications or treatment techniques illustrates suggestions; she is not endorsing any specific products.

Sites from the Heart

Special Needs Advocates Share Their Caring Online

by Vanessa B. Ira

It happens often enough. When the parent or caregiver of a child with a disability realizes that the work they give to one child is so important, they feel compelled to do even more. Serving the children they love is such a powerful elixir that many of these caregivers still try to find ways of reaching out to others who may be going through their ordeal for the first time.

The Internet has made it easy for parents and caregivers to share such knowledge and experience. Following are some sites that were created by those individuals. There are many more out there which EXCEPTIONAL PARENT will cover in the future.

- IRSC.ORG (http://www.irsc.org)—The Information Resources for Special Children (IRSC) Web site was created by a parent of a child with multiple disabilities, born in 1983, who felt the need to share all the valuable information he has so far gathered. The heart of the site is a long list of links to disability sites which are marked by the date they were added to clearly show which ones are current. Archived links go back to 1997.
- NJTRUSTEKIDS.ORG (http://www.njtrustekids.org)—The Children's Emergency Medical Fund of New Jersey has set up this child-friendly site containing links to Web sites with resources to brighten up the days of homebound kids with disabilities: wholesome children's games, Great Books, electronic greeting cards and more. The idea behind providing those interactive tools is an extension of the Fund's overall mission to enhance the quality of the "Truste Kids" lives. It keeps the children's lines open to the world of caregivers, doctors and other children, 24 hours a day. The site also provides useful resources for the caregivers, such as links to sites about foundations and grants; medical resources; and "sites for mom."
- PACER CENTER (http://www.pacer.org) —The Parent Advocacy Coalition for Educational Rights (PACER) Center's Web Site offers a motherlode of disability resources including: Legislative Information; Employment Strategies for Youth and Adults with Disabilities; information on IDEA; and a section on Emotional Behavioral Disorders. A newly added resource called "TA Alliance" links to information on the Technical Assistance Alliance for Parent Centers, funded by the U.S. Department of Education, Office of Special Education Programs. The Alliance offers resources to assist the Parent Centers in strengthening their ability to serve the families with children who have disabilities. **EP**

E-mail your comments on this article, or other ideas or suggestions for EParent.com, to: Vanessa B. Ira, Internet Projects Advisor and Consultant, at: vira@eparent.com. Or call (201) 634-6550 ext. 213.

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Circle #18

PART 2

Strength in the Face of Adversity

Last month, we introduced our readers to the Crowley family from Pennington, New Jersey, our newest inductees into the "EP Hall of Fame." Parents John and Aileen spoke to us about caring for their three children, John Jr., 5, Megan, 3, and Patrick, 18 months. Megan and Patrick both have Pompe's disease, a rare muscular disorder.

Pompe's disease is caused by a genetic defect that prevents the body from producing a crucial enzyme called acid maltase. In healthy individuals, acid maltase breaks down sugars that are stored in the body's muscle cells. In Pompe's disease, the absence or insufficiency of acid maltase forces the body to continually store sugar in the muscle cells in the form of glycogen. Glycogen storage rapidly causes the muscle cells to deteriorate. This results in progressive weakening and deterioration of the muscles. Glycogen also accumulates in the liver, muscles, nerves, and heart, preventing them from functioning properly.

The demands of the disorder have invaded every aspect of the family's life and prompted their efforts to raise funds for research into the disease. It has forced them to be their own advocates when dealing with their insurance carrier. This is the second part of our interview with the Crowley family, as they relate their experience in their own words.

MEDICAL EXPENSES

The level of care that Megan and Patrick need every day, around the clock is extremely costly. John and Aileen have managed to convert the insurance companies from adversaries into partners, by making them see the human side of Megan and Patrick's illness.

JOHN CROWLEY: The care for Megan and Patrick at home and the 24-hour nursing care alone is a quarter of a million dollars a year. Beyond that are the equipment, visits to the doctors, and hospital stays. Fortunately we have not had many of those this year. All together, Megan and Patrick's medical care runs close to $500,000 per year. We are very fortunate in working for Bristol Meyers Squibb. It is a company that is dedicated not only to its customers but also to its employees in its mission of extending and enhancing human life. They have helped tremendously with the financial burden of this.

The insurance company, United Healthcare, has been great, too. But this has required many discussions.

When we first took Megan and Patrick home, the insurance company told us we will get 24-hour nursing care for a couple of weeks, then 16 hours, then they said they believe that having a child on a ventilator is a home care skill they could teach us and then we won't have nursing care. I just said from day one that is absolutely not possible, not acceptable, and fought very hard. I think they realized the uniqueness of this situation and the unique needs, and since that time have been very supportive. For example, the nurses that United Healthcare originally provided through their agency were uniformly horrible. We fired about 22 of them for gross incompetence.

The Crowley family at home (l-r): Aileen, holding Patrick; John Jr.; and Megan, with John Sr.

How one family meets the challenge of debilitating illness

Megan Crowley gets star treatment at one of the fund raisers [illegible] The Children's Pompe Foundation.

After a couple of months I just said stop. We can find better nursing care with the money you are giving these agencies.

The insurance company was very flexible in working out an agreement with us to allow us to directly hire the nurses and to pay them directly.

AILEEN CROWLEY: There is no middleman getting a cut and therefore we have excellent nurses.

JOHN: As a result, we interview and choose our own nurses ourselves.

John and Aileen have been their own advocates with their insurance carrier.

JOHN: When they (the insurance carrier) wouldn't listen, I went to our HR (human resources) people and our benefits people and told them the story. You have to put a very human side to it and try to explain to them in very layman's terms what it's like living in the house without nursing care, and it's impossible. The alternative is to institutionalize the child, and that's something that is completely, as a lifestyle, completely unacceptable to us.

It also did not make economic sense for them. So you have to make arguments on a number of different grounds and realize that at the end of the day, these are people with kids, too.

AILEEN: They have their certain rules that are outrageous. When Patrick came home from the hospital, they said they would pay for two nurses in the home at a lesser price. I said I don't want two nurses at a cheap price. I want one nurse that we can pay good money to. They said we don't do that. That doesn't make any sense, they were going to pay double, pay for two nurses, when they could have paid for one nurse.

JOHN: Once it was explained to them, they understood and they became very flexible and very supportive. Without that support I don't know what we would be able to do. There are other programs, there are state programs, the state catastrophic medical insurance fund, Medicaid, but fortunately we have been able to navigate through the private insurance right now.

We probably have $30,000 a year unreimbursed, uncovered medical expenses.

THE NURSE AND THE AU PAIR

The Crowley household benefits from the services of two live-in caregivers, Sharon (a nurse) and Ann (an au pair), who live downstairs in the Crowley's house. They are always available to provide whatever help is needed.

AILEEN: Sharon is wonderful with the children. She also deals with the surgical supply company, and she is tough, she is on their case if they are not here.

She always has been a travelling nurse. She and Ann have become good friends. It's hard having strangers in your house all the time. It's so rare that John and I are ever alone. They give us our space and they get their own space downstairs.

It's hard to have non-family members living in your house, but they are very respectful as we are of their privacy, too. Downstairs is theirs pretty much, they have their own TV and couch and refrigerator and stuff. Sharon needs her time away, too; she puts in 12-14 hour days with kids every day that she is here. They have become part of the family. The kids are very excited about Ann's birthday.

We lucked out with Ann, so many people have stories with au pairs and how things just don't work out. She wanted to learn how to take care of Megan and would take shifts at the hospital. Megan was in the hospital for six weeks first, and she and Patrick were in the hospital last March for 3-4 weeks. We all took shifts. Ann took the night shift some nights. She did more than most family members.

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ADVICE TO OTHER PARENTS

JOHN: People have different ways of coping, different ways of taking care of their children; different ways of dealing with it. There is no one right way of doing it.

We were determined to fight the disease and I guess my recommendation for parents in similar situations is to be as curious and as challenging as you can, always respectful, but curious and challenging.

The doctor in California, the pediatric neurologist who diagnosed Megan, told us that day he did not know of any research going on. It was an extremely rare disease and, according to a footnote in his medical textbook, Megan had about two months to live. I didn't know anything about rare genetic diseases. I knew there were hundreds of thousands of them. I didn't know how they got cured, how they got treated, who works on them.

Then we found out very quickly on the Internet, first of all, that there were doctors working on it. So my first advice is to find out who the top doctors are, who are writing the papers on these diseases, which have done PhD theses on them. Then contact the doctors, see where they are in their research, see where their funding levels are. I had always assumed that if the researcher thought he had the cure to it, or was close to a cure, that he would find research money—from industry, government, families, foundations, somewhere. I found three or four doctors working on Pompe's disease who had virtually no funding at all.

It was very frustrating. You are hopeful, knowing that there are doctors working on a cure for Pompe's disease. But because there wasn't enough funding, your child isn't going to have access to it, and it may never be developed, or not for a long time. That was something that we are determined to change. For parents in that situation, I would say never give up, keep driving, always challenge, and always learn. You will find that doctors and researchers will welcome your support, even just to tell you and teach you about their research.

THE CHILDREN'S POMPE FOUNDATION

JOHN: The past year, we started our fundraising in November of 1998. Altogether we have raised about a million and a half-dollars in a little over a year. It started with a letter-writing campaign to friends and family. When they know about it, they'll tell ten friends, and they will tell ten friends. The media exposure has been helpful, too.

AILEEN: We get lots of encouraging letters, too, which is nice.

JOHN: Some letters are from people who can sympathize or empathize, because they've had a child who died. We've gotten letters from people who've read the story in national magazines and they will tell us that they had a brother who died of Pompe's disease in 1960. Their dream is that this gets cured, and they send $50 in his memory. Or we hear from parents of children who have disabil-

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Patrick cuddles with Sharon, the live-in nurse who takes care of Patrick and Megan's medical needs.

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ities or disorders who can empathize with us. Then we will get letters from people who are thankful who say, they have beautiful, healthy grandchildren, and couldn't imagine what we are going through. I thank God that we are healthy and we are sorry your family isn't and here's what we can do to help.

AILEEN: It's amazing. One Sunday school Nursery School all wrote letters. It was nice.

JOHN: They had a bake sale, it was a preschool, and they raised about $90, in fact I have to tell you because after they raised $97.10. They each sent a letter; we had no idea that this was going on.

Megan relaxes at home with her au pair, Ann, who is part of the team that cares for the Crowley children.

One of the 5-year-olds wrote in the letter, Dear Mr. and Mrs. Crowley, I am sorry to hear about Megan and Patrick. I hope they get better soon. We tried to raise a lot of money for you, but we didn't do really good, we only got 97 bucks. She signed it, and the teacher made her put a line through the part that said we really didn't do really good, we only raised 97 bucks. From the mouths of babes. I've kept all those letters.

AILEEN: I want Patrick and Megan to read them.

JOHN: Megan and Patrick better be pretty good kids when they grow up. I'll say to them, "You want to stay out *how* late? Let me tell you about what I did for you when you were a kid..." **EP**

For more information, contact the Children's Pompe Foundation:
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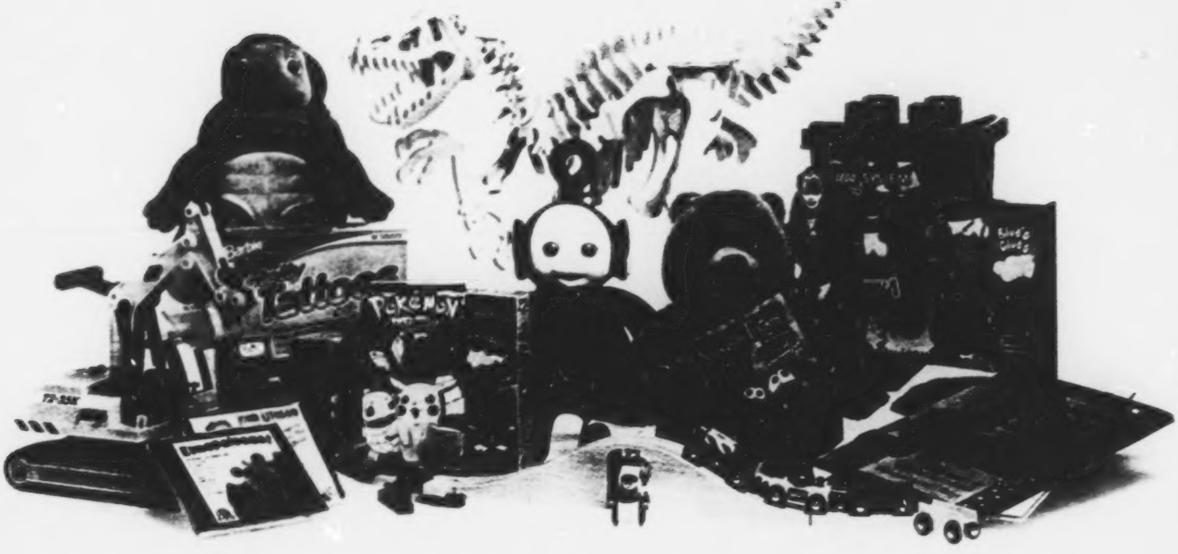

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Part 2

PARENTS' PERSPECTIVES ON AAC:
Making sense of technology and making it work

by Peggi McNairn, PhD, CCC/SLP, ATP, and Cindy Shioleno, MEd

With the realization that their children will require technology to assist and support them in their lives, parents often enter a world alien to them. This is a world filled with "techno-jargon" and foreign gadgets. That was the case for Ed and Brenda Klauditz family of Toms River, New Jersey. "When Daniel was born seventeen years ago, we really did not realize the extent that he would be disabled. As it turned out, Daniel has cerebral palsy and is very involved," reflects Brenda. "By the time Daniel was 2 years old, I was on a mission to find a way that he could communicate," she recalls. "He was very frustrated. Even though I am a master of guessing and my son the master of cluing, the better I got, the more complicated the things he wanted to say became. So we were both in need of something better."

The Urschel family: Christi, Dr. Hal, and their 4-year-old son Chance.

AUGMENTATIVE AND ALTERNATIVE COMMUNICATION

According to the American Speech-Language-Hearing Association (ASHA), augmentative and alternative communication systems, or AAC, "refer to all communication that supplements or augments speech." AAC covers a broad range of techniques, strategies, and devices, from simple picture boards to sophisticated, computer-based communication devices with synthetic voices. Other examples of augmentative and alternative communication may include facial expressions, gestures, body postures, sign language, drawing, and writing.

LIGHT TECH AAC DEVICES

Simple augmentative communication devices that do not use electronic or computer parts, such as the use of pictures attached to a board or inexpensive devices that can record a voice, are often referred to as "light-" or "low-" tech devices. For young children, light-tech options may be the first type of AAC that is introduced. These simple devices are typically used to facilitate the development of emerging language and communication skills. Light-tech devices should be introduced early because they use skills that children may have mastered, such as pointing with their hands or even their eyes.

However, even light-tech AAC options can prove overwhelming, time-consuming, and cumbersome. For Dr. Hal and Christi Urschel of Dallas, Texas, the introduction of a light-tech system to their 4-year-old son, Chance, was particularly challenging. One of the light-tech AAC devices that Chance uses has pictures attached to a clear, plastic square panel. Beginning with only four pictures, Chance quickly moved to twelve pictures that he selected by pointing with his eyes. The Urschels make sure that someone works with Chance and his AAC device every day. "Being able to implement even simple technology in only a few of his daily activities, such as eating, bathing, and playtime, requires a significant amount of consistency and continued enhancement of his system."

HIGH TECH AAC DEVICES

Often, because light-tech systems are simple, they may also prove to be very limiting. When this occurs, high-tech AAC systems should be introduced.

[illegible] communicating with his technology.

Parents of children who use augmentative and alternative communication (AAC) devices share helpful information, stories, and insights about their experiences with the process of selecting and using communication systems.

Today there are many high-tech communication devices on the market. Some devices are manufactured specifically for communication. These are referred to as "dedicated" communication devices. Although these devices may perform many functions similar to those of a computer, they do not often resemble one.

Laura Warburg of Louisville, Kentucky, the mother of 8-year-old Candice, says the use of a dedicated AAC device strengthens her daughter's ability to communicate verbally. Born with cerebral palsy, Candice did not have a way to communicate when she began kindergarten. However, her mother reports that, "Today, she has a DynaVox mounted to her wheelchair. She studies for spelling tests and tells jokes with it." Brenda Klauditz believes that "without the technology, Daniel would not have a chance at this life of his because he is so physically involved. He enjoys his technology."

A second type of high-tech communication device is called "integrated." Using the computer as a base, special software is added to enhance the computer's ability to function as a communication device. According to Dr. Urschel, "Once we decided to choose a standard laptop computer, we realized that, in addition to the many benefits it has for Chance, it is also familiar to other people and consequently, it is less threatening for them to interact with him."

Most dedicated and integrated AAC devices offer some form of voice output. The voices in these devices are referred to as either "synthesized" or "digitized." Synthesized speech is produced artificially by a computer program. Digitized speech refers to sounds and speech that are recorded and stored in the device. Some devices now offer both synthesized and digitized voice options.

LIGHT TECH VS. HIGH TECH

The use of light-tech devices does not exclude the additional use of high-tech AAC devices. In fact, AAC is most effective when thought of as a "system" rather than a specific device or piece of equipment. The greater the variety of communication options that a child has to choose from, the better opportunity he or she will have in communicating his or her thoughts in every situation. Using this systems approach avoids the many pitfalls of relying on only one device or technique. If a high-tech system breaks down and needs repair, light-tech systems can serve in the interim. Also, some situations, such as bath time, may not lend themselves to the use of a high-tech system. "I believe that we need to use both high- and light-tech devices," says Mrs. Klauditz. "There is a place for both. When making choices on which device to use, the user's needs should be the priority."

MATCHING NEEDS

Before any system can be successful, the needs of the child and family must be the first consideration of the AAC assessment team. There are many factors that will influence the successful implementation of any AAC device. These factors include: vocabulary and icon selection; weight; appearance; and portability of the device; ease of programming the device; access and positioning; and funding options.

These systems must also be capable of growing and expanding with the child's changing needs. "We needed a system that helped us prove what Candice was learning at school and one that enhanced her early reading and language development," recalls Laura Warburg. "Because of our late entry into the high-tech AAC game, we also needed a device that would help Candice express herself in the social situations she was starting to crave."

VOCABULARY AND ICON SELECTION

Choosing the best way to represent language in a picture or word format is one of the most difficult tasks for an assessment team. Decisions must be made as to the use of pictures or words to represent what the child wants to say to others. Within this vocabulary selection format, there is a range of options to consider. Vocabulary may be programmed to relate to a specific activity that occurs during the child's day—a core vocabulary of general, frequently used words or a combination of both approaches. It is important that the team stay focused and committed to the common goal of assisting the child to become a successful communicator.

Weight, appearance, and portability will affect the every day use of the device. A heavy device may be an important issue for a small child who may have difficulty carrying it.

Ease of programming and use are also important factors to be considered in the

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assessment process. Devices that are difficult or confusing to program will often intimidate people who are unfamiliar with or new to technology. Training and technical support from device manufacturers, either on site or over the telephone, is critical for successful implementation to take place.

How the child will physically control the device will often determine which products are appropriate. Not all children with physical challenges may be able to use their hands and fingers to touch the keys on a computer or communication device. Many children will need an alternate way to access their devices. Enlarged keyboards and screens, special keyguards, and wireless infrared remote controls are only a few options available for high-tech access. This was one of the first challenges that faced the Urschel family.

"In our son's particular case," observes Dr. Urschel, "because of significant motor impairments, we needed to remove the motor component from his communication as much as we could to allow him to communicate at a normal speed." Today, Chance is learning to communicate and read using a special, hands-free infrared mouse attached to his laptop computer.

Finding the appropriate funding source for technology is also important during the assessment process. Although overcoming funding barriers may seem like an overwhelming obstacle for some families, there are many funding options available, including public and private resources. Insurance, grants, and private foundations may provide funding for communication devices. Another resource available to families may be their public school systems. The federal law, Individuals with Disabilities Education Act (IDEA), mandates the "purchasing, leasing, or otherwise providing for the acquisition of assistive technology devices by children with disabilities."

MEETING THE NEEDS OF THE FAMILY

During the assessment process, meeting the needs of the family is just as important

RESOURCES

An excellent resource of information for parents on the many devices currently available is the Communication Aid Manufacturer's Association (CAMA). CAMA hosts workshops in various parts of the United States throughout the year, highlighting the products of various AAC device manufacturers. They can be reached at (800) 441-2262.

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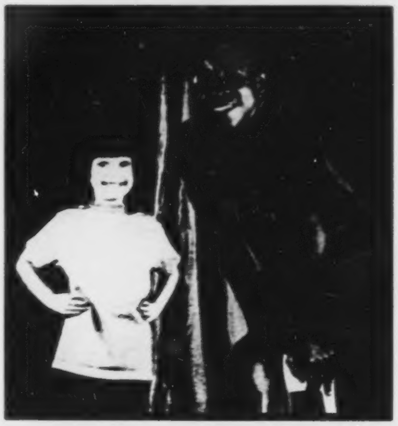

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as meeting the needs of the child. Understanding where families are in this process will have a powerful impact on the use of technology in the home. "A team approach to understanding, acceptance, and emotional levels would have been a huge factor with us as we learned about cerebral palsy," reflects Laura Warburg. "We needed to be led to the water instead of being told where the water was. We would have gained so much, in those early days *and* today, from one-on-one mentoring of a family with an older child with similar abilities. ACOLUG (Augmentative Communicator's Online Users Group) does that for me now."

The Warburgs (clockwise from top) Laura, Frank, Candice, and Joey

The Urschel family agrees that support from knowledgeable professionals and making the technology part of daily living is important. The greatest challenge we have faced is to actually implement the technology into our household and our lives. Eventually, we hope to act as a model for other families and attempt to pass on the basic concepts that we have learned so that everyone can benefit from our lessons," reflects Dr. Urschel. In spite of all these challenges, the Urschels, the Warburgs, and the Klauditzes all agree that being able to communicate with their children is the greatest reward. **EP**

The authors welcome questions and comments.

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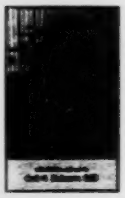

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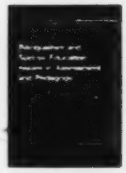

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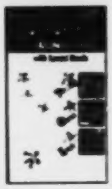

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Washington, DC 20005
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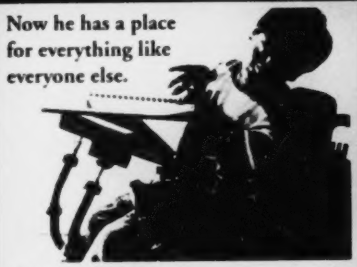
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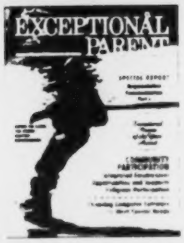

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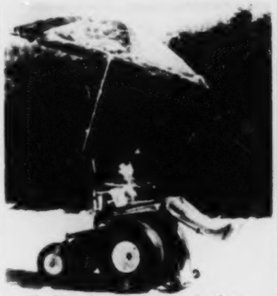

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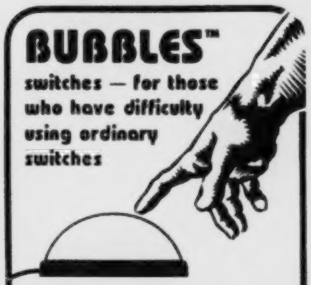

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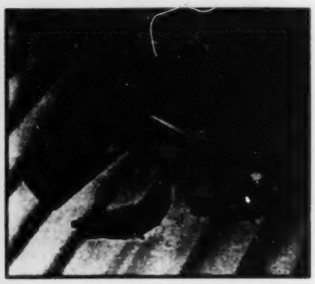

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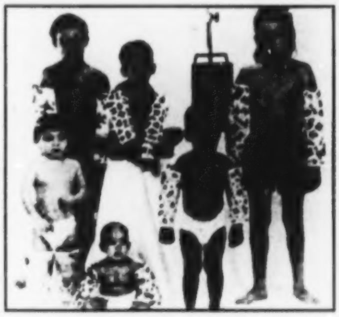

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The ABLEDATA database of assistive technology and rehabilitation equipment contains information on more than 25,000 products for persons of all ages who have a physical, cognitive, or sensory disability. Products are chosen for this page by the ABLEDATA staff based on their specific applicability to or design for children who have disabilities. ABLEDATA, operated by Macro International Inc., is funded by the National Institute on Disability and Rehabilitation Research under contract number HN-96015001.

For more information on these and other assistive devices, or to submit product information for the database (and possible inclusion on this page), contact: **ABLEDATA, 8401 Colesville Rd., Ste. 200, Silver Spring, MD 20910; (800) 227-0216 or (301) 608-8998 (voice); (301) 608-8912 (TTY); (301) 608-8958 (fax); Web site: http://www.abledata.com.**

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Remembering Devin

by Troy Huizinga

Pretend right now that you cannot walk or talk. You have both a visual and hearing impairment, and have seizures all the time.

I had an older brother named Devin who had all of these disabilities. A lot of people thought my brother could not do anything, that it would be weird to be his brother; but it was not like that at all. Devin was born with all his disabilities, and I cannot imagine him any other way. He could not walk, but I pushed him in his wheelchair. He could not speak, but I could understand him. I got used to his noises and faces, and sometimes, I would have to tell my parents what he wanted.

Devin swam, bowled, fished, camped, played hockey, and even went tobogganing.

As long as he had a life jacket and someone there to hold him, Devin was awesome in the water. He went bowling with his class and he would often have the highest score. A special wooden ramp was placed up to the wheelchair and the bowling ball was put into his hand. The ball then rolled down the ramp and if Devin was lucky...STRIKE!!

Devin liked to go fishing. He was better than me, of course. He had a lot more practice at sitting still and being patient.

Devin learned to play hockey at school. He would sit on a special sled-like seat with runners on the bottom. Someone would sit behind him to help him hold the hockey stick as they glided across the ice. Devin even scored a goal!

Devin went tobogganing, *once*. My dad laid Devin down on the toboggan and before we knew what happened, Devin was shooting down the slope with my dad charging after him! Devin looked like a bobsledder in the Olympics, and I have never seen my dad run that fast.

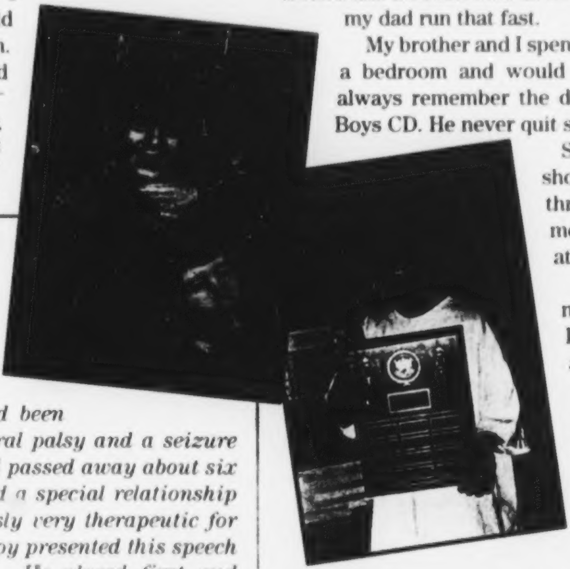
My brother and I spent a lot of time together. We shared a bedroom and would listen to music at night. I will always remember the day I bought our first Backstreet Boys CD. He never quit smiling!

Sometimes, when we would go out shopping and I would push Devin through the stores, it would make me angry when people would stare at him. I thought they were rude.

My brother Devin passed away not too long ago, and I miss him. Even with his disabilities, he did a lot.

With a little help, people can do anything! **EP**

Troy Huizinga, 10, lives in Ontario, Canada, with his mom, Joy, dad, Ken, and brother, Luke, 6.



(Top left) Devin at age 9 with his dog, Lucy. (Right) a Christmas portrait with Troy at age 3, and Devin at age 5. (Far right) Troy with his public speaking award.

Mom's Turn:

My son Troy's grade four class were asked to write a speech and present it. It was a surprise to find that Troy had written this speech about his older brother, Devin. Devin had been medically fragile (he had cerebral palsy and a seizure disorder) his entire life and had passed away about six months earlier. Troy always had a special relationship with Devin, and it was obviously very therapeutic for him to talk about his brother. Troy presented this speech in a school-wide competition. He placed first and eventually won first place at the Division Level. His most memorable event was when he was the guest speaker at a fundraising event. He received a standing ovation. Troy has helped the rest of our family deal with Devin's death through his wonderful story.

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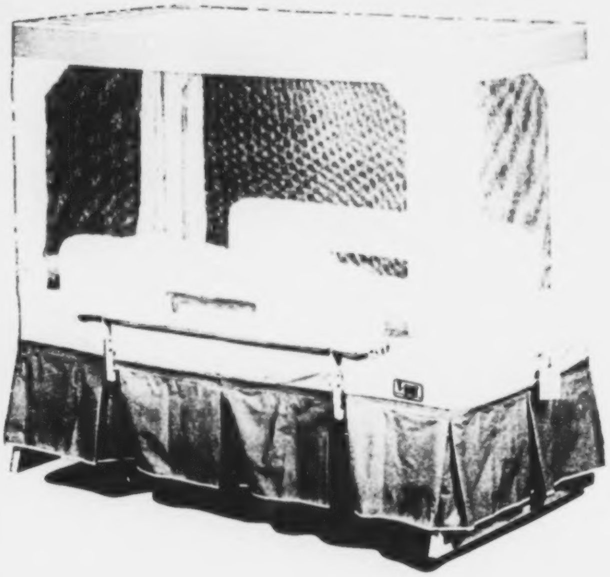

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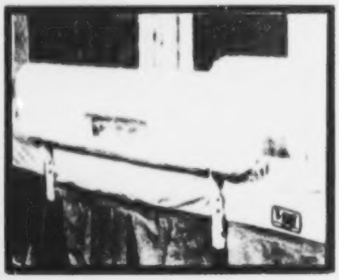

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levocarnitine
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Levocarnitine deficiency is defined biochemically as abnormally low plasma levels of free carnitine, (less than 20 μmol/L at one week post term) and may be associated with low tissue and/or urine levels. Further, this condition may be associated with a ratio of plasma ester/free levocarnitine levels greater than 0.4 or abnormally elevated levels of esterified levocarnitine in the urine. In premature infants and newborns, secondary deficiency is defined as plasma free levocarnitine levels below age related normal levels.

BIOAVAILABILITY/PHARMACOKINETICS

In a relative bioavailability study in 15 healthy adult male volunteers CARNITOR® Tablets were found to be bio-equivalent to CARNITOR® Oral Solution. Following the administration of 1980 mg b.i.d., the maximum plasma concentration level (C_{max}) was 80 nmol/mL and the time to maximum concentration (T_{max}) occurred at 3.3 hours. There were no significant differences for AUC and urinary excretion observed between these two formulations.

In the same bioavailability study of 15 healthy adult males, CARNITOR® (levocarnitine) Injection administered as a slow 3 minute bolus intravenous injection at a dose of 20 mg/kg showed that free levocarnitine plasma profiles are best fit by a two compartment model. Approximately 76% of free levocarnitine is eliminated in the urine. Using plasma levels uncorrected for endogenous levocarnitine, the mean distribution half life was 0.585 hours and the mean apparent terminal elimination half life was 17.4 hours following a single intravenous dose.

The absolute bioavailability of L-carnitine from CARNITOR® Tablets and Oral Solution was determined compared to the bioavailability of L-carnitine from CARNITOR® Injection Intravenous in 15 healthy male volunteers. After correction for circulating endogenous levels of L-carnitine in the plasma, absolute bioavailability was 15.1% ± 5.3% for L-carnitine from CARNITOR® Tablets and 15.9% ± 4.9% from the Oral Solution.

Total body clearance of L-carnitine (Dose/AUC including endogenous baseline levels) was a mean of 4.00 L/hr. Endogenous baseline levels were not subtracted since total body clearance of L-carnitine does not distinguish between exogenous sources of L-carnitine and endogenously synthesized L-carnitine. Volume of distribution of the intravenously administered dose above baseline endogenous levels was calculated to be a mean of 29.0 L ± 7.1 L (approximately 0.39 L/kg) which is an underestimate of the true volume of distribution since plasma L-carnitine is known to equilibrate slowly with, for instance, muscle L-carnitine.

L-carnitine was not bound to plasma protein or albumin when tested at any concentration or with any species including the human.

INDICATIONS AND USAGE

CARNITOR® (levocarnitine) is indicated in the treatment of primary systemic carnitine deficiency. In the reported cases, the clinical presentation consisted of recurrent episodes of Reye-like encephalopathy, hypoketotic hypoglycemia, and/or cardiomyopathy. Associated symptoms included hypotonia, muscle weakness and failure to thrive. A diagnosis of primary carnitine deficiency requires that serum, red cell and/or tissue carnitine levels be low and that the patient does not have a primary defect in fatty acid or organic acid oxidation (see Clinical Pharmacology). In some patients, particularly those presenting with cardiomyopathy, carnitine supplementation rapidly alleviated signs and symptoms. Treatment should include, in addition to carnitine, supportive and other therapy as indicated by the condition of the patient.

CARNITOR® (levocarnitine) is also indicated for acute and chronic treatment of patients with an inborn error of metabolism that results in a secondary carnitine deficiency.

CONTRAINDICATIONS

None known.

WARNINGS

None.

PRECAUTIONS

General

CARNITOR® (levocarnitine) Oral Solution is for oral/internal use only.

Not for parenteral use.

Gastrointestinal reactions may result from too rapid consumption of carnitine. CARNITOR® (levocarnitine) Oral Solution may be consumed alone, or dissolved in drinks or other liquid foods to reduce taste fatigue. It should be consumed slowly and doses should be spaced evenly throughout the day to maximize tolerance.

Carcinogenesis, mutagenesis, impairment of fertility

Mutagenicity tests performed in *Salmonella typhimurium*, *Saccharomyces cerevisiae*, and *Schizosaccharomyces pombe* indicate that CARNITOR® (levocarnitine) is not mutagenic. Long-term animal studies have not been conducted to evaluate the carcinogenicity of the compound.

PREGNANCY

Pregnancy Category B.

Reproductive studies have been performed in rats and rabbits at doses up to 3.8 times the human dose on the basis of surface area and have revealed no evidence of impaired fertility or harm to the fetus due to CARNITOR®. There are, however, no adequate and well controlled studies in pregnant women. Because animal reproduction studies are not always predictive of human response, this drug should be used during pregnancy only if clearly needed.

NURSING MOTHERS

It is not known whether this drug is excreted in human milk. Because many drugs are excreted in human milk, a decision should be made whether to discontinue nursing or to discontinue the drug, taking into account the importance of the drug to the mother.

PEDIATRIC USE

See Dosage and Administration.

ADVERSE REACTIONS

Various mild gastrointestinal complaints have been reported during the long-term administration of oral L- or D,L-carnitine; these include transient nausea and vomiting, abdominal cramps, and diarrhea. Mild myasthenia has been described only in uremic patients receiving D,L-carnitine. Gastrointestinal adverse reactions with CARNITOR® (levocarnitine) Oral Solution dissolved in liquids might be avoided by a slow consumption of the solution or by a greater dilution. Decreasing the dosage often diminishes or eliminates drug-related patient body odor or gastrointestinal symptoms when present. Tolerance should be monitored very closely during the first week of administration, and after any dosage increases.

Seizures have been reported to occur in patients with or without pre-existing seizure activity receiving either oral or intravenous levocarnitine. In patients with pre-existing seizure activity, an increase in seizure frequency and/or severity has been reported.

OVERDOSAGE

There have been no reports of toxicity from carnitine overdosage. The oral LD_{50} of levocarnitine in mice is 19.2 g/kg. Carnitine may cause diarrhea. Overdosage should be treated with supportive care.

DOSAGE AND ADMINISTRATION

CARNITOR® (levocarnitine) Tablets.

Adults: The recommended oral dosage for adults is 990 mg two or three times a day using the 330 mg tablets, depending on clinical response.

Infants and children: The recommended oral dosage for infants and children is between 50 and 100 mg/kg/day in divided doses, with a maximum of 3 g/day. Dosage should begin at 50 mg/kg/day. The exact dosage will depend on clinical response.

Monitoring should include periodic blood chemistries, vital signs, plasma carnitine concentrations and overall clinical condition.

CARNITOR® (levocarnitine) Oral Solution.
For oral use only. **Not for parenteral use.**

Adults: The recommended dosage of levocarnitine is 1 to 3 g/day for a 50 kg subject, which is equivalent to 10 to 30 mL/day of CARNITOR® (levocarnitine) Oral Solution. Higher doses should be administered only with caution and only where clinical and biochemical considerations make it seem likely that higher doses will be of benefit. Dosage should start at 1 g/day, (10 mL/day), and be increased slowly while assessing tolerance and therapeutic response. Monitoring should include periodic blood chemistries, vital signs, plasma carnitine concentrations, and overall clinical condition.

Infants and children: The recommended dosage of levocarnitine is 50 to 100 mg/kg/day which is equivalent to 0.5 mL/kg/day CARNITOR® (levocarnitine) Oral Solution. Higher doses should be administered only with caution and only where clinical and biochemical considerations make it seem likely that higher doses will be of benefit. Dosage should start at 50 mg/kg/day, and be increased slowly to a maximum of 3 g/day (30 mL/day) while assessing tolerance and therapeutic response. Monitoring should include periodic blood chemistries, vital signs, plasma carnitine concentrations, and overall clinical condition.

CARNITOR® (levocarnitine) Oral Solution may be consumed alone or dissolved in drink or other liquid food. Doses should be spaced evenly throughout the day (every three or four hours) preferably during or following meals and should be consumed slowly in order to maximize tolerance.

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Cover: Arton Kucana, 22, who has developmental delays, is from New York City. He is a student in the District 75 Travel Training Program. Thanks to the program, Arton, who uses a motorized wheelchair, can now take a city bus for a trip to the zoo. The article "Travel Training: Getting out and about without fear" begins on page 26.

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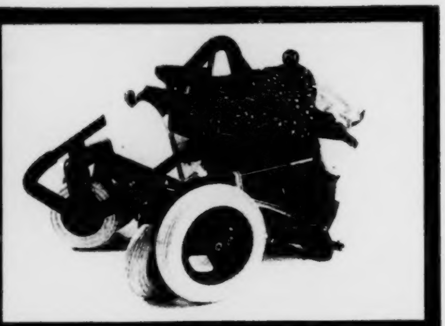

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EDITOR'S DESK

Mobility 2000

Mobility is a crucial part of the development of all children. Separating and becoming independent is a life long process that begins at birth. Physical limitations change the way independence develops. Over the past decade, there has been an enormous advance and improvement in mobility devices. This month, physical therapists Ginny Paleg and Steve Mauricio describe the use of self-propelled standers. These wheeled devices enable children to experience the feelings of stand and motion. Their article, "Stand and Deliver: Guide to self-propelled Standers" also contains a detailed evaluation of the devices that can help parents find their way through a thicket of standards and features and select what is most appropriate for their child.

Mobility can also be affected by intellectual as well as physical limitations. Travel training, which is included in the IDEA '97 (Individuals with Disabilities Education Act), helps individuals develop an awareness of the "outside" world and develop the skills to move effectively and safely from place to place. In "Travel Training: Getting out and about without fear," Margaret Groce, supervisor of the New York City Board of Education's Travel Training Program, discusses what parents can expect from the training and how it should be done to ensure safety and success for a child.

For many young people who use wheelchairs, getting to and from school or activities necessitates transportation in a van or bus. Only recently has serious attention been paid to the issue of correct positioning and securing of people who are being transported in their wheelchairs. In "New Developments in Safer Transportation for Wheelchair Users," Dr. Lawrence Schneider reviews the latest standards and pending mandates for wheelchair "tie downs" to ensure that occupants of wheelchairs are secured safely during the ride.

Our *Role Model* for April is Jim Jeffreys, a young man who was born without hips or legs. Jim is a wheelchair athlete and a graduate student at William Paterson University in Wayne, New Jersey. Jim succeeded in bringing the University community together to raise awareness about disability through a wheelchair basketball game that included athletes with and without disabilities. He and his family have inspired his fellow students and faculty at the University with their courage and persistence.

Critical findings on IDEA implementation

In January, the National Council on Disability (NCD) released a study on the implementation of IDEA in America's education systems. Parents who have written to EP with their experiences of having their child's educational needs denied will not be surprised by the pervasive problems the NCD found. Each state in the Union was found to be non-compliant with IDEA to some degree, and some have committed extensive violations of the law. The NCD recommended that the Department of Justice be involved in handling parental complaints and that the Department of Education establish and use national standards for evaluating each state's progress toward compliance.

Judy Heumann, assistant secretary of the U.S. Department of Education's Office of Special Education and Rehabilitative Services (OSERS), responded by discussing the great progress that has been made in the education of children with special needs. She indicated. that some of the problems described have been addressed and named a series of innovative programs that have been implemented. We have always been impressed by the dedication and ability of the OSERS staff and their commitment to IDEA and its implementation. However, over the past 20 years we have also been aware of consistent budget cuts in funding for monitoring of all federal programs, including OSERS. The shortage of monitors has allowed states and local communities to ignore their responsibilities; no matter the dedication of the OSERS staff, without the ability to monitor and enforce the laws, little will change.

Legislative update

Family Voices is an important parent organization which has made a significant impact on ensuring support for medical care for children with disabilities. This month, the group's National Communications Development Coordinator, Julie Keys, has written about the report "Your Voice Counts!" that Family Voices presented to Congress, and she has also reported on the pending legislation for this Congressional Session that affects people with disabilities and requires support.

Special technology

With technology changing ever more rapidly, many of us are at a loss to keep up with the information. Parents of children with disabilities cannot afford to be left in the dark about technology and what it provides. In "Assistive Technology 101," R.J. Cooper discusses the basics of what to look for when purchasing the computer equipment to support assistive technology.

Augmentative and alternative communication is a subcategory of assistive technology. In "Can We Talk." Part 3, Peggi McNairn and Cindy Shioleno continue their excellent series. This month, they look at choosing the system that is right for your child.

Maxwell J. Schleifer, PhD
Editor-in-Chief

Conference Calendar

- EP is proud to be collaborating with the MassGeneral Hospital for Children on their conference and exhibit, Humanizing Health Care for Children and Families: The Art of the Relationship, which will take place in Boston, Massachusetts, May 28-31, 2000. Among the topics to be discussed at the conference are: family-centered care, community/school integration, spiritual care, and emotional support.

- This fall, EP will co-sponsor The World Congress & Exposition on Disabilities (WCD) (November 10-12, 2000 in Atlanta, Georgia). Come join us as we host this forum for individuals who have disabilities and their families, with leading experts on disability-related fields who will share their knowledge and experience. For more information, contact the WCD at: (877) 923-3976, or (201) 226-1446; Web site: http://www.wcdexpo.com

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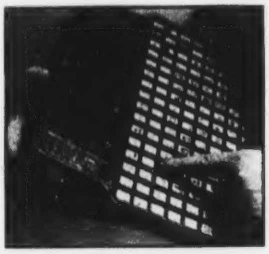

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- *To appreciate that parents are the most important experts in the lives of their children.*
- *To energize parents and professionals.*
- *To share ideas and experiences so parents, professionals, people who have disabilities, and other advocates can learn from one another and better collaborate to serve all children and families.*

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HELEN TAGER-FLUSBERG, PH.D, Senior Scientist, Eunice Kennedy Shriver Ctr for Mental Retardation and Developmental Disabilities, Waltham, MA

LAWRENCE T. TAFT, M.D., Professor of Pediatrics, University of Medicine and Dentistry of NJ, Robert Wood Johnson Medical School, New Brunswick, NJ

CAROL TINGEY, Ph.D., Parent, Psychologist, University of Utah Hospital, Salt Lake City, UT

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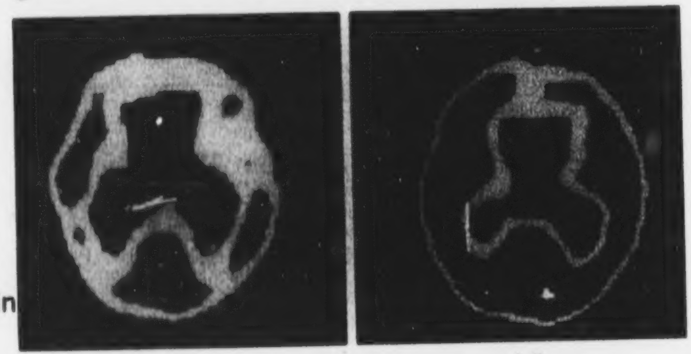

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Circle #58

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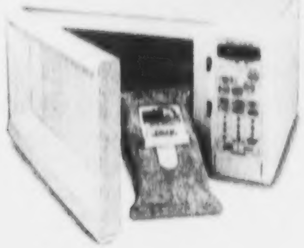

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Good Housekeeping Promises

Circle #74

Search & Respond

Search and Respond is an opportunity for our readers to exchange information about their practical experiences in meeting the everyday challenges of life with a child or adolescent who has a disability. In this column, "S" represents Search letters and "R" represents Respond letters received to a previously printed Search. "Instant S&R" is a new feature which represents e-correspondence we have downloaded from our Web site. All Responds are forwarded to the writers of the original Searches; some are published. Published letters may be edited for purposes of space and clarity. We also expect parents to consult appropriate professionals.

When sending correspondence, please indicate whether it is a Search or a Respond. For Responds, be sure to note in which issue the original Search letter appeared. Please remember to include a phone number on all correspondence, in the event that more information is required. Write to: Exceptional Parent, Attn: Search/Respond, 555 Kinderkamack Rd., Oradell, NJ 07649-1517; Fax to: (201) 634-6570; E-mail to epedit@aol.com; or visit Search and Respond on our Web Site: http://www.eparent.com.

For information about specific disabilities, contact: the National Organization for Rare Disorders (NORD), 100 Rt. 37, PO Box 8923, New Fairfield, CT 06812; (800) 999-6673; (203) 746-6518; Web site: http://www.rarediseases.org. Also, see the "National Resources for Specific Disabilities" directory in Exceptional Parent's 2000 Resource Guide (January 2000, starting page 30).

Each month, Chris Feudtner, MD, PhD, reviews Search & Respond for accuracy and completeness. Dr. Feudtner is a pediatrician at the Pediatric Care Center of the University of Washington in Seattle, and is currently a Robert Wood Johnson Clinical Scholar. Look for Dr. Feudtner's comments on certain Search & Respond letters.

S Chromosome 13q- syndrome

I work in an early-intervention program, and I am seeing a family whose 14-month-old son was recently diagnosed as having Chromosome 13q- syndrome. (This is a rare disorder in which part of the long arm of the 13th chromosome is missing. It is characterized by craniofacial malformations, limb abnormalities, poor growth, and psychomotor delays). The child is at increased risk for developing retinoblastomas (cancerous tumors of the eye) before age 5 and osteosarcomas (cancerous tumors of the bone) after age 8. He has already had one retinoblastoma removed. The baby is globally delayed (functioning at about half his chronological age), but he is improving. The family is eager to communicate with other families who have a child with chromosome 13q- syndrome, especially in Colorado or the western US.

R. S., Grand Junction, CO

EDITOR'S NOTE: You may want to contact Chromosome Deletion Outreach, Inc., PO Box 724, Boca Raton, Fl [illegible]3429-0724; (516) 391-5098; E-mail: [illegible]worldnet.att.net; Web site: http://mem[illegible]rs.aol.com/cdousa/cdo.htm; or the National Retinoblastoma Parent Group, PO Box 317, Watertown, MA 02471; E-mail: napvi@perkins.pvt.k12.ma.us.

Swallowing

S My 4-year-old son is undiagnosed after genetic testing, an EEG, and an MRI. He is delayed in all motor skills and speech. He also has a high-arched palate and receding chin. We had a G-tube inserted because he is not able to swallow. He has been seen by occupational and speech therapists, but neither has helped him with swallowing. He is making improvements in the other areas of development, but I am at the end of my rope with the swallowing. Any information would be helpful.

L. C., via the EP Web site

Genetic syndrome?

S I have two sons with special health needs. My 9-year-old son has cerebral palsy and periventricular leukomalacia (white matter volume loss and immature myelination). Now my previously healthy 2-year-old son has been diagnosed with myoclonus (a neurological movement disorder characterized by sudden, involuntary contractions of the skeletal muscles). I am wondering if my two sons' problems are related. I am looking for more information about myoclonus and whether there are any treatments besides medications. I would also appreciate information on programs in New York that will help us adapt our home and purchase equipment for the boys.

A. B., New York, NY

S Patterson-Lowry rhizomelic dysplasia

My 10-year-old son was diagnosed as having Patterson-Lowry rhizomelic dysplasia (a rare skeletal disorder that is characterized by shortening of the long bones, especially the arms; coxa vara, where the thigh bone is angled toward the center of the body; short stature; and limited shoulder motion). We have encountered many medical problems including: epilepsy, learning problems, coxa vara that required surgery, and dyspraxia (difficulty performing tasks that require coordination). We are not sure if he has been diagnosed correctly and would appreciate any information.

L. T., LaCrosse, WI

Dr. Feudtner: *You may wish to discuss with your physician the possibility of a consultation at a major center that deals with rare chondrodysplasias.*

EDITOR'S NOTE: You may want to contact the International Center for Skeletal Dysplasia, Saint Joseph's Hospital, 7620 York Road, Towson, MD 21204; (410) 337-1250.

S Custom buggy

I have a 7-year-old daughter who has cerebral palsy, microcephaly, and epilepsy. I recently found out that I am pregnant. I will desperately need a double buggy to transport both children. My older daughter requires good support due to her physical problems. I have tried everywhere here in the UK and have not come up with any possibilities. I would appreciate any advice or contacts, even in the States.

Elaine, via the EP Web site

continued on page 20

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The Stockton features full crib safety sides

Beds for children once they pass the crib stage are always an issue with parents... I can't begin to tell you how terrific the people at HARD Mfg. are. Mary Bias, the rep for the Indiana area told me she knew exactly what I wanted and needed for Nicholas. Thirty-days later the Stockton Bed arrived and it couldn't be more perfect! The Stockton comes in three sizes, with crib type rails, and a height adjustment up to 34"...saving my back! It even has a mounted IV pole for Nicholas' feeding pump. Mary had also suggested the white bed with a red outer footboard and yellow inner headboard...

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Dianna Fitzgerald

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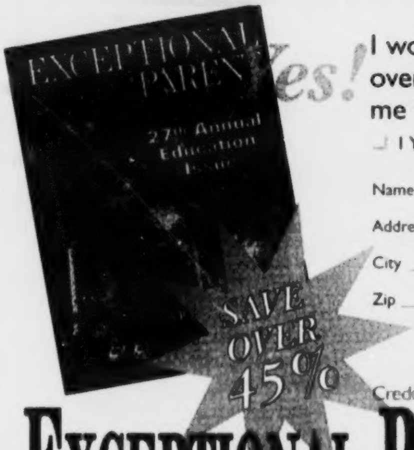

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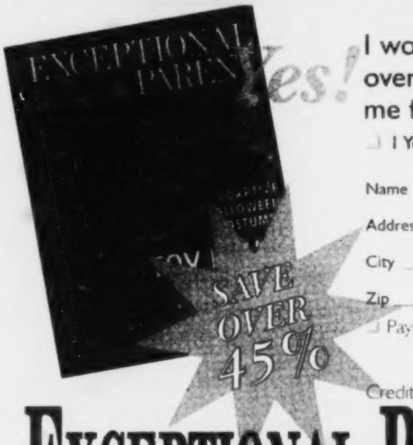

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Exceptional Parent

is the magazine for parents and professionals involved in the care and development of children and young adults with special needs, including Physical Disabilities, Developmental Disabilities, Mental Retardation, Autism, Epilepsy, Learning Disabilities, Perceptual Disabilities, Hearing Impairments, Vision Impairments, Emotional Problems, Chronic Illness.

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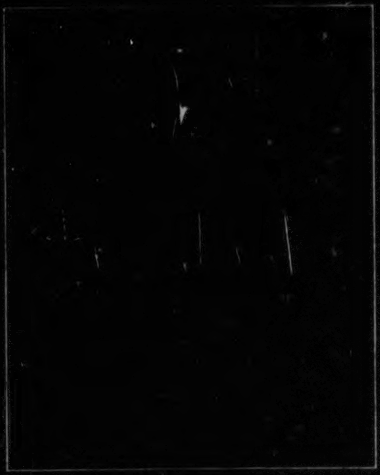

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Circle #38

Search & Respond

continued from page 14

S Portable potty

My ten-year-old daughter has cerebral palsy, is non-ambulatory, and cannot talk. When we go to use public restrooms, it is very difficult for me as her caregiver to constantly hold her on a regular toilet bowl. I am in search of a portable potty that can be placed on a regular-sized toilet bowl—one that has sides (so she will not fall over) and is foldable (to fit in a dia per bag).

J.S., via email

R Probable mitochondrial metabolic disorder

H.H., December 1999 (via the EP Web site), has a son who is undiagnosed. He has feeding difficulties, a seizure disorder, developmental delay, and a high level of lactic acid in the blood. She requested information on further testing to help determine a diagnosis, and also wanted ideas on seizure medications that would not make the mitochondrial disorder worse.

My 2-year-old daughter has the same symptoms and was diagnosed with a peroxisomal disorder. (Peroxisomes work to rid the body of toxic substances.) She has some characteristics of infantile Refsum syndrome (a rare disorder of lipid, or fat, metabolism) and some of neonatal leukodystrophy (a rare, progressive, genetic metabolic disorder that affects the brain, spinal cord, and nerves). My daughter is also like a 6-month-old. She cannot walk, talk, or sit up. Her head control is still poor, and she suffers from seizures as well. She is currently on liquid Depakote®, which has reduced the length of time of the seizures from 20 to 7 minutes (approximately). My advice is to ask your doctors to consider a skin biopsy before a muscle biopsy (so as to be less invasive), and to check the blood levels of the "very long fatty acids" that accumulate in people who have peroxisomal disorders.

Dolores, via the EP Web site

R Respite Care

Marcy, Feb 2000 (via the EP Web site), requested information on obtaining respite care for her two children with severe disabilities. Her family lives in Michigan.

Contact your local community mental health (CMH) board. They should be listed in the phone book in the government section. Respite is an important area for families with children with special needs, and great efforts have been made in funding for respite. In our county, respite is available about every 6 weeks. The CMH may also have funds for home nursing. Check with your insurance first, as many good policies will cover this need, particularly if one spouse has to travel for his or her job.

Clay, via the EP Web site

Instant S&R

S Undiagnosed

I have a 20-month-old daughter with severe delays. She has a heart defect, uncoordinated swallowing (she is fed via a G-tube), growth deficiency, short limbs, simian crease (a single crease across the palm) on right palm, reflux, and neurological issues. All tests, including chromosome tests, have come back normal. We would love to know more about her future.

Amy, via the EP Web site

R Undiagnosed

I have a 9-year-old daughter who is severely mentally impaired. She functions at about the level of a 2-year-old. At birth, she had several defects including: cleft palate, missing thumbs on both hands, chromosome translocation (portions of the chromosome are broken and attach to other chromosomes) of 1 and 16, heart defects, feeding disorder, and gastroesophageal reflux disease. She has some hearing loss, but even so is hypersensitive to sound. She is tactile defensive. She also had the simian crease in both hands. At 4 months of age, she had her cleft palate repaired. At 7 months, she had her index fingers turned into thumbs (they look and work wonderfully well!) She has a G-tube and has had two fundoplications (construction of a new "valve" between the stomach and the esophagus) to stop the reflux. She has Barrett esophagus (chronic inflammation of the esophagus due to reflux). We have been to several doctors and clinics with no diagnosis or syndrome named.

My daughter is a happy child who loves to wrestle and give kisses. We do not know what her prognosis will be in the future, so we treasure each day we have with her. It has been a difficult and long 9 years. All I can offer you is to love your daughter for what she is and not to worry about what she is not. It is hard for me not to feel sorry for my daughter or myself, but my pediatrician has a great way of putting it. He says that in my daughter's world she is the happiest kid on Earth, and he is right. We try to focus on the things that she has learned to do and pray that she continue learning the small things. If anyone has a child similar to our daughter, we would also appreciate any advice or support you can give.

Mary, via the EP Web site

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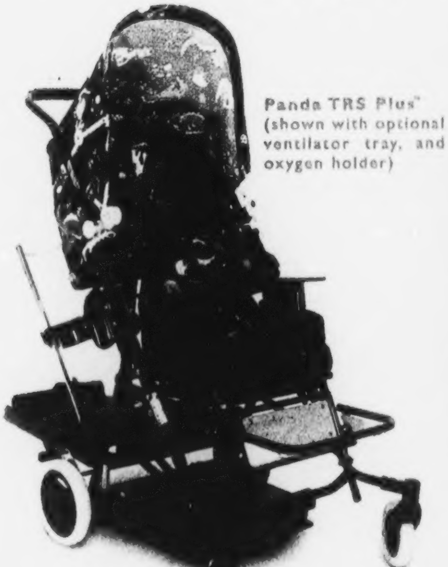

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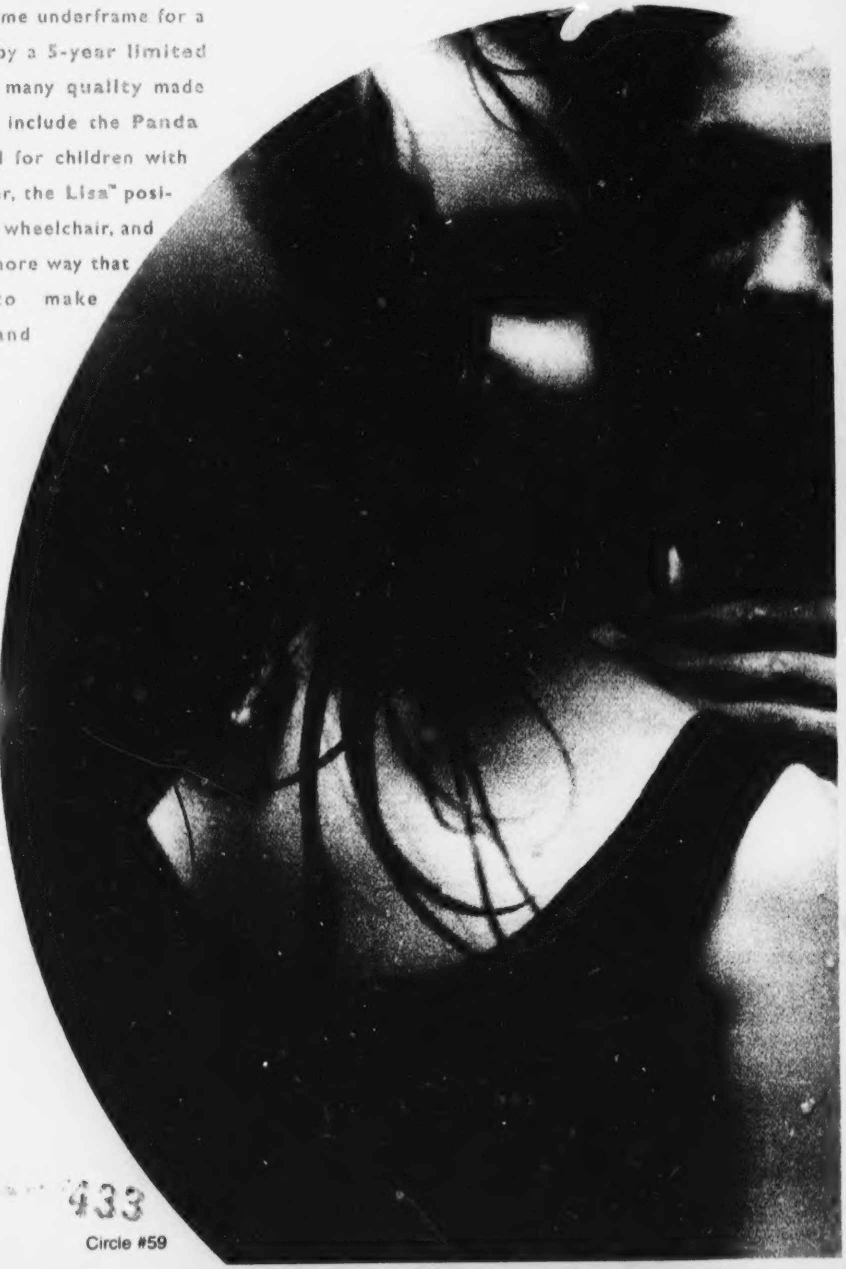

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Circle #59

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WHAT'S HAPPENING

Welcome additions to our Web site!

Send us photos of your child for our Familiar Faces and Children's Page columns, and they will not only be in print, they will also be seen in cyberspace! EXCEPTIONAL PARENT *has added Familiar Faces and Children's Page to our Web site (http://www.eparent.com). This will make sharing pictures that appear in* EXCEPTIONAL PARENT *more convenient, because now all you have to do is give friends and family our Web address and they can see the entire article for themselves.*

CPSC and National SAFE KIDS Campaign announce crib safety initiative

The US Consumer Product Safety Commission (CPSC) and the National SAFE KIDS Campaign announced a crib and play-yard safety initiative to keep children safe when traveling with their families. Recent spot checks by SAFE KIDS found unsafe cribs and play yards in 80 percent of the 90 hotels and motels visited throughout 27 states and the District of Columbia. Of the cribs inspected, 82 percent had at least one safety hazard including loose hardware or lack of a secured mattress. Of the play yards and mesh cribs inspected, 52 percent had at least one safety violation.

CPSC and SAFE KIDS have prepared information that hotels and motels, as well as consumers, can use to make sure cribs and play yards are not hazardous. The crib and play-yard safety inspection checklist and CPSC crib safety and recall information are

continued on page 24

CALENDAR OF EVENTS

MAY 4-7

International Parent to Parent Conference 2000
"Pioneering Spirit Blazing New Trails"
RENO, HILTON, RENO, NV

This conference brings together families from across the United States and all around the world. Topics will include support, education, medical and health issues, and the Parent to Parent philosophy. For more information call (775) 747-1771; Web site: http://www.unr.edu/repc/npm.

MAY 6-7

18th Annual Cincinnati Wheelchair Games and Sport Expo
CINCINNATI, OH RECREATION COMMISSION, DIVISION OF THERAPEUTIC RECREATION
SYCAMORE HIGH SCHOOL, 7400 CORNELL RD., CINCINNATI, OH

Events will include swimming, track and field, triathlon, vendor booths, wellness seminars, and more. For more information call Heidi Bunker at (513) 352-4056.

MAY 12-14

Abilities Expo
ANAHEIM CONVENTION CENTER, ANAHEIM, CA

This conference will show the latest in assistive living products and services, as well as seminars on insurance coverage, government regulations, and available services. For information call (800) 382-3085, Web site: http://www.abilitiesexpo.com.

MAY 12-16

Advancing Children's Health 2000
Pediatric Academic Society and American Academy of Pediatrics
HYNES CONVENTION CENTER, BOSTON, MA

Topics will include ADHD: Guidelines for Office Practice and advocacy training. For more information, call (281) 419-0052; fax: (281) 419-0082; Web site: http://www.aps-spr.org.

MAY 12-19

American Occupational Health Conference
PENNSYLVANIA CONVENTION CENTER, PHILADELPHIA, PA

Topics will include The Future of Health Care: Debating the Issues and The Impact of the Complete Human Genome. For more information call (847) 818-1800 or go to their Web site at http://www.acoem.org.

MAY 22-24

Nursing Care of the Hospitalized Child
NEW ORLEANS, LA

This conference is for pediatric nursing professionals who care for children. Goals of this conference are to strengthen advanced physical assessment skills, understand the psychological impact of illnesses in the lives of children and families, and exchange ideas and approaches with colleagues. For more information call (925) 828-7100 x0.

MAY 28-31

MassGeneral Hospital for Children Conference 2000
"Humanizing Healthcare for Children and Families: The Art of the Relationship"
WESTIN HOTEL COPLEY PLACE BOSTON, MA

The goal of this conference is to provide individuals with a forum to come together as advocates for children and families. For more information call (617) 724-5720.

MAY 25-28

The 6th National Conference on Hydrocephalus for Families and Professionals
LA POSADA RESORT, SCOTTSDALE, AZ

Topics will include trends in research, comprehensive pediatric care, complex hydrocephalus and Dandy-Walker syndrome, and alternative treatments. For more information contact the Hydrocephalus Association at (888) 598-3789; Fax: (415) 732-704; Web site: http://www .hydroassoc.org; or E-mail: hydroassoc@aol.com.

MAY 30-June 2

Association for the Care of Children's Health, 34th Annual Conference
"Kids Need More Than Medicine to Get Well"
HYATT REGENCY, LONG BEACH, CA

Topics will include pediatric pain awareness, learning to enhance healing through the family, using imagery and meditation for stress and pain reduction. For information call (562) 933-8050.

MAY 30-June 3

American Association on Mental Retardation 124th Annual Meeting
HILTON, WASHINGTON, DC

Topics that will be discussed are ethics, genetics and self determination. For more information call (800) 424-3688; Web site: http://www.aamr.org; or E-mail mward@ aamr. org.

Just This Side of Normal: Glimpses Into Life With Autism

BY ELIZABETH KING GERLACH

Published: 1999, Four Leaf Press. 139 pages.

Available through the EP Library: (800) 535-1910: code FL101AT.

Cost: $19.95 plus shipping and handling.

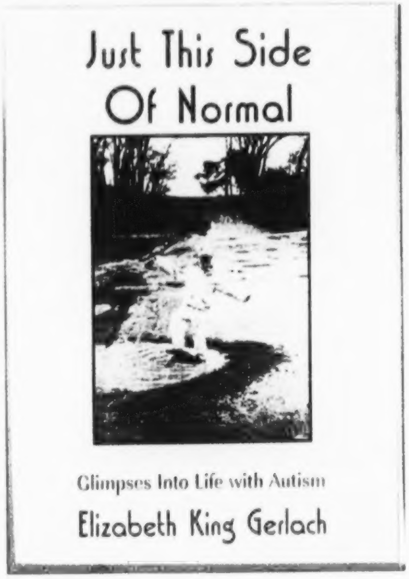
In the pages of her recently published book, Elizabeth King Gerlach, author of *Autism Treatment Guide* and founder of the parent advocacy group, Mothers From Hell, shares a very personal account of life with her son Nicky, 12, who has autism. *Just This Side of Normal* is a story told through brief episodes Elizabeth recounts, some revolving around the trials and stresses of caring for Nicky, and some celebrating breakthroughs that served to renew and deepen the bonds between parent and child.

One example of the heart-wrenching emotions that a parent of a child with autism experiences is captured in passages like this:

"Every time I give Nicky a kiss he wipes it away with his hand as if it were repulsive. I know it isn't me; I know it is a 'sensory issue' or a 'compulsive act,' more features of autism. Understanding doesn't make this small act hurt any less.

One day I blurt out, 'Please don't wipe my kiss away, rub it in and make it stay.' Something about the rhyme makes him laugh. Something in him is freed up. Perhaps he understands the importance the kiss carries for both of us. Perhaps he wants to oblige me in this small happiness?

'Kiss me again,' he insists. The hand brushes up to the cheek in the usual fashion, but this time he smiles and says, 'I rub it in and make it stay. Kiss me again.'"



Advocating for their child's rights in school is another facet of life for parents of children with disabilities. Elizabeth describes her experiences in the front lines, attending her son's school Individualized Education Plan (IEP) meeting. The meeting includes seven school-district personnel. Elizabeth feels it is imperative that Nicky remain where he is. He is comfortable and familiar with the school, and has been improving. She feels uncomfortable and intimidated:

"I wonder how often the administration banks on this subconscious fear and feeling of inadequacy, and on the lack of power the typical parent like me must feel. We are so very out of place. Neither a student nor a teacher. Our children are viewed as 'problems.'

The tester removes his glasses and runs his fingers over his eyes as though he has a headache. He has tested my son's cognitive skills. He has administered the test without consulting us as to what might have been used (stickers, M&Ms...) to motivate Nicky to answer the questions. We wanted Nicky's scores to reflect his usual cognitive abilities, not his ability to 'test.'

'The results,' he informs me, shaking his head, 'would indicate that your son is a nonreader.' He drones on for another twenty minutes, finishing with the pronouncement, 'Your son's placement at this school has been a failure.'

Shock and rage boil inside me like lava. I erupt.

'My son has learned how to walk in a line, he has learned how to raise his hand, he has learned how to sit in class, he no longer runs away, he has participated in school performances. How dare you call my son's time here a failure!' I hardly believe my own voice. I am shaking. The insensitivity of this man is the last straw. Having just completed a special education law class this term, I quote the 'stay put' provision, which guarantees a parent's right to appeal any decision regarding a change in their child's placement.

The atmosphere in the room changes. The teacher is in tears. The principal assures me that it can be worked out. This seems like a bad dream."

At the end of the book, Nicky is 12 years old. Elizabeth reflects during the rare quiet time of early morning while looking in on her sleeping sons:

"I wouldn't, couldn't, have imagined the complexities of mothering a child with autism—the struggles, the heartaches, the opportunities to learn and love. Once these boys were only the dream of a girl who wanted to be a mother. Now they are two living 'wishes come true,' with wishes of their own. What new dreams and possibilities are yet to be for them?"

Excerpts reprinted with permission from the author.

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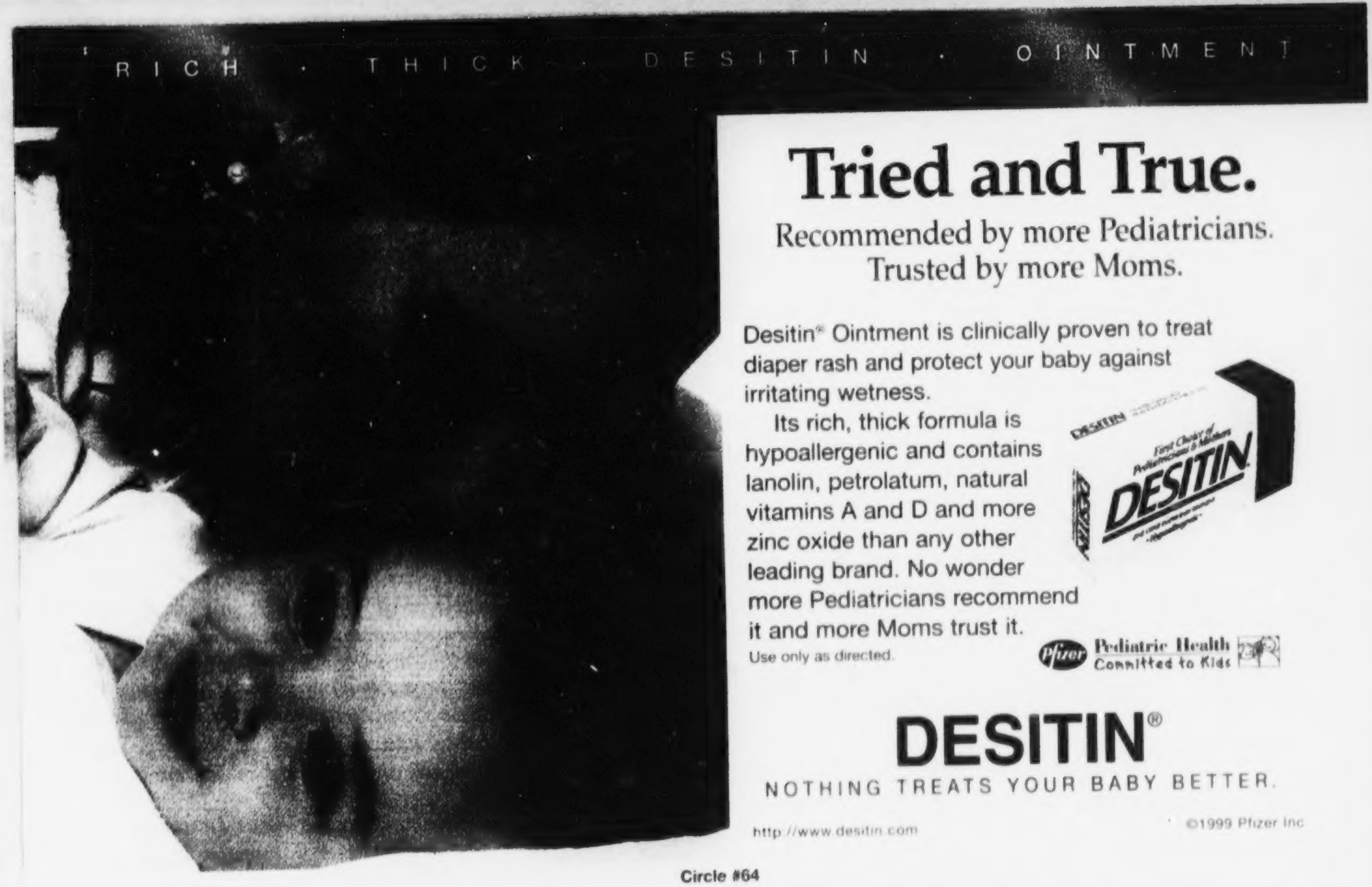
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Circle #64

WHAT'S HAPPENING

continued from page 22

available on the CPSC Web site at http://www.cpsc.gov; or by calling their hotline at (800) 638-2772.

Recall information

In cooperation with the CPSC, Nordstrom Inc., is recalling approximately 2,250 infant and toddler jackets. Snaps located on the flap pockets of these jackets could be removed, presenting a choking hazard. The recalled garments were made in pink or blue gingham fabric with a hood and flap pockets. Consumers should stop using these jackets immediately and return them to any Nordstrom store for a refund. For more information, call Nordstrom at (800) 695-8000.

The U.S. Consumer Product Safety Commission protects the public from unreasonable risk of injury or death from 15,000 types of consumer products under the agency's jurisdiction. To report a dangerous product or product-related injury and for information on CPSC's fax-on-demand service, call their hotline at (800) 638-2772 or CPSC's teletypewriter at (800) 638-8270. Consumers can obtain this release and recall information at CPSC's Web site: http://www. cpsc.gov. Consumers can report product hazards via E-mail at info@cpsc. gov.

"Your Own World," children's Web site, launches nationwide

Your Own World (YOW), a free, Internet-based service provides the best of the Web within a closed offline environment for children aged 2-12. This unique service allows children the freedom to surf the Web, and gives parents the peace of mind that their child is viewing safe, appropriate material. Parents follow a simple point and click installation process from a free CD ROM. During YOW installation, parents and their children select

Corrections

In the December 1999 issue, the story on Mike Utley, EP's Exceptional Person of the Year, contained two errors. The correct spelling of the President of the Mike Utley Foundation is George Dempsey. The correct phone number for the foundation is (602) 224-0909. We apologize to Mr. Dempsey and regret both errors.

Resource Guide Correction:
The correct listing for the Wyoming Title V Program Contact is:
Children's Health Services
Department of Health
Division of Public Health
Hathaway Bldg., 4th fl
Cheyenne, WY 82002
(800) 438-5795
(307) 777-7941
(307) 777-7215 (fax)
E-mail: DAILES@state.wy.us

Update:
The correct address for the National Perinatal Association is 3500 East Fletcher Ave., Ste. 205, Tampa, Fl 33613-4712. They now have a toll free number as well: (888) 971-3295.

"channels" of content from leading children's Web sites and CD ROMs that are appropriate for each child's age, reading level, and special interests. After installation, children launch the service from their PC desktop without ever actually going online. YOW's software uses the Internet to automatically update content daily in the background at any time a parent selects.

The following sites have already joined YOW: BrainPop.com, a site devoted to health, science, and technology; Hiyay.com, a site that offers a multimedia collection of classic children's stories; Knowable.com, which offers a wide variety of online animation, games, and activities in various educational subjects; and others. This service is provided by Passport New Media, Inc., a company dedicated to addressing the performance and safety issues that children and their parents face when using the Internet. For more information, visit YOW's Web site at http://www.yourownworld.com.

Australia's Access Expo 2000

Access Expo 2000, Australia's most comprehensive exhibition of products and services for people with disabilities or their caregivers will be held October 22-24 at the Australian Technology Park and Convention Centre. The Expo will be held to coincide with the 2000 Paralympic Games in Sydney, Australia. The displays will include travel options, computer technology, mobility aids, transport and vehicle modifications, employment options, and much more. There will be demonstrations of new, adapted leisure and recreational activities, and a diverse range of seminars will be conducted. For further information, contact Julie Stein at +61 3 94151200; E-mail: jstein@paraquad.asn.au; Web site: http://www.paraquad.asn.au/expoi/expo.

Starbright empowers children

The Starbright Foundation, a nonprofit organization dedicated to the creation of projects that empower children and teens who are seriously ill, is offering free video and CD ROM programs to children and their families. The videos include "Videos with Attitude (1, 2, & 3)," which features teenagers discussing strategies and solutions for adjusting to hospital life, communicating with their health-care team, and returning to school after an illness or injury.

The Starbright Explorer Series is an interactive CD-ROM that gives children the opportunity to explore behind-the-scenes medical procedures and learn about medical conditions. For more information on Starbright, call (310) 442-1560; Web site: http://www. starbright.org.

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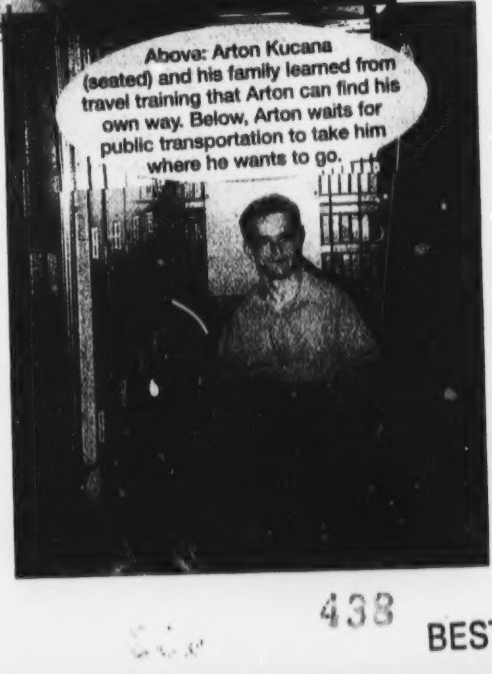
Circle #65

TRAVEL TRAINING: GETTING OUT AND ABOUT WITHOUT FEAR

Independent mobility in the community—the ability to safely navigate public places and use public transportation to get to school, a job, or to visit a museum or a friend—is a basic part of enjoying life. Too often, however, it is an option that is overlooked or dismissed as too dangerous for young people with disabilities. The good news is that the skills needed for successful self-directed travel can be taught and the need for this training is recognized under IDEA.

By Margaret M. Groce

Margaret Groce supervises New York City's Board of Education District 75 Travel Training Program. For 30 years, the Program has been responsible for training many students to get around in one of the biggest, busiest cities in the world. In this article, she describes what a parent can expect from a good program and how young people with disabilities can learn to safely travel wherever the road, and their dreams, will take them.



Above: Arton Kucana (seated) and his family learned from travel training that Arton can find his own way. Below, Arton waits for public transportation to take him where he wants to go.

Having the ability to travel independently and at will provides a vital key to achieving participation in society. For young people with disabilities, travel training is a way to gain the necessary skills to travel on their own. Travel training is specially designed instruction provided to students with disabilities (other than blindness or visual impairments) to enable them to safely negotiate public environments and use public transportation as independent travelers. In addition to its contribution to independence, travel training also has financial benefits since the cost of using public transportation is significantly less than that of using a contracted private car or bus service.

How is travel training provided?

The instructional program is short-term, comprehensive, and individualized to the student's needs and abilities. The training is one-to-one and takes place in the natural environments in which the student is expected to travel.

Most students start travel training at about the age for transition: between 15 and 21. Some children may be ready for training at an earlier age, however. Younger students and those who are not ready to learn to travel independently may require additional instruction in basic mobility and travel-related skills and concepts.

Taking the first steps:

In the District 75 Travel Training Program, a summer component aims to provide purposeful movement and basic mobility/travel skills. Examples of these skills include: moving through a school building independently; waiting in line; self-identification (how to identify oneself to appropriate officials and get any assistance needed); opening doors; walking on the right side of the hallway; reading signs; following environmental cues (such as sounds, smells and colors that indicate where one is and what one should do. For example, the sound of a fire alarm indicates that one needs to leave the building, and not wait for a teacher to say, "Line up."); using an elevator; and using telephones.

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This instruction in basic mobility and travel-related skills generally occurs in small group settings in a classroom. During this instructional program, the concept and experience of traveling in the community and using public transportation is introduced with an emphasis on the skills and behaviors needed for safety.

Independent travel:

Before beginning travel training, the students are assessed on functional, cognitive, physical, and behavioral skills related to travel, such as: "initiating" actions (how to know when it is time to cross the street), self-identification, and using money. In addition, students must have a good understanding of and ability to use basic skills such as: knowing where their personal space ends and that of others begins; an awareness of their environment; and the ability to recognize and respond to danger. If the assessment indicates that the student can profit from travel training, parental permission and student consent for the instruction and independent travel is then secured.

Hitting the road:

Following the assessment of the student, a travel route is selected from the individual's home to the destination point and back to home.

Choosing the best route:

One-to-one instruction is individualized to meet the needs and preferences of the student and family. Selecting the appropriate route for the individual is

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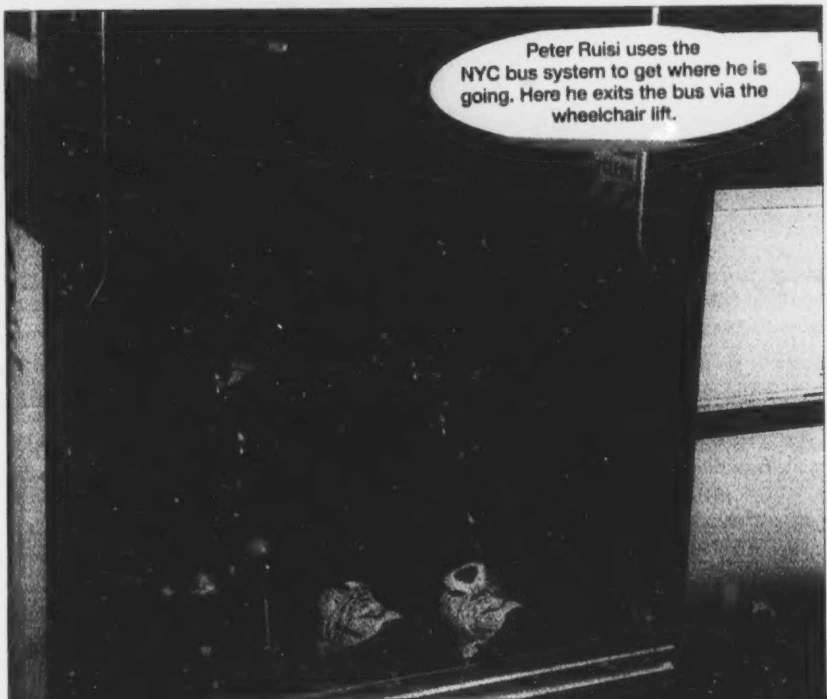
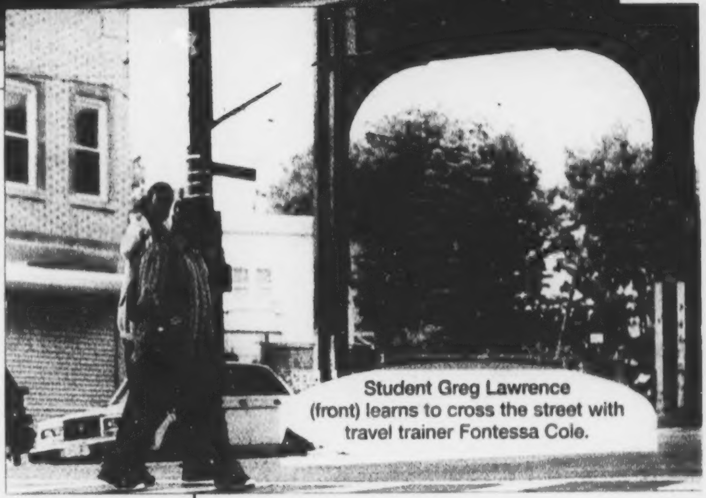


Peter Ruisi uses the NYC bus system to get where he is going. Here he exits the bus via the wheelchair lift.



Student Greg Lawrence (front) learns to cross the street with travel trainer Fontessa Cole.

TAKING IT TO THE STREETS

Parent experiences with travel training

"Getting Eron to school was very difficult," writes Helen Lewis, a parent in New York City, whose son Eron, 17, has developmental disabilities. According to his mother, Eron could not be allowed to walk anywhere unaccompanied and did not like the school bus. "I had to take him to and from school with very little time for other things." Though Mrs. Lewis did not see a way out, the Travel Training Program of District 75 was able to provide the answer. "At first I was very skeptical about Travel Training," she writes. Mrs. Lewis' concern is common among parents, especially those whose children have cognitive impairments. The suggestion that their child with disabilities learn to travel independently and use public transportation creates anxiety and fear among many parents.

Underlying parents' fears is their belief that their children are too vulnerable to travel independently. At the same time, parents want their children to grow up to be as independent as possible. In order for this dream to become reality, their children need to acquire the essential skills and behaviors, including the use of public transit. That's where travel training by skilled professionals comes in.

Mrs. Lewis agreed to let Eron try the Program and was impressed with its trainers. "From the very first moment Gerard came to my door he was very professional in the way he took charge of the situation. He spoke to Eron in an authoritative way. I didn't expect it but Eron listened to him. Right there and then I knew I was doing the right thing. In a matter of days I realized that the possibility of Eron traveling by himself was becoming a reality."

Now, Mrs. Lewis notes, her son insists on going to school by himself and even travels to the corner store. "I have seen a big change in him—in his schoolwork and his confidence. Eron has become so independent that sometimes I forget he has a disability."

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Joseph Scimeca negotiates the NYC subway system in his manual wheelchair.

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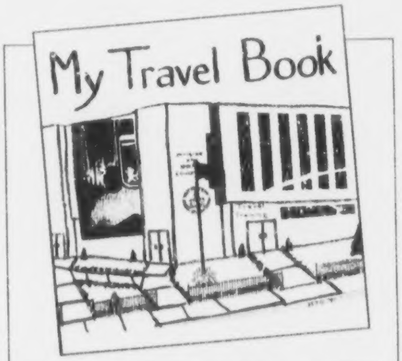
an important part of the instructional plan. Some families might not want their child using the subway system or may not want the child to travel down a certain street or on a side of a certain street. The travel route is evaluated to determine the safety and suitability of the environment for the student including social conditions, type of neighborhood, availability of shelter, traffic, intersections, distance, time, and transit options. The time of day of actual travel for the student is important. A route may be safe and suitable during rush hour travel but not at off-peak times.

The one-to-one instruction occurs at the time the student will usually travel. This enables the travel trainer to evaluate the student's ability to handle the actual travel environments safely and make modifications or changes in the route if necessary. Travel training typically begins at the student's home in the morning and ends at the same place later in the day.

Travel essentials:

Every student receives intensive instruction in essential travel skills with the opportunity to practice the skills in the natural environment of travel. Essential travel skills include: crossing streets safely, with and without traffic signals; responding appropriately to strangers; knowing what to do if lost or disoriented; requesting assistance from an appropriate source (and declining assistance from inappropriate sources); recognizing and avoiding danger or obstacles; using the telephone or other systems of communicating; dealing with unexpected situations in the travel environment; boarding, riding, and exiting the appropriate transit vehicles; recognizing and disembarking at the correct destination; maintaining appropriate behavior; and having the ability to make decisions and follow directions.

Last year, 17-year-old Elliot Sarlo, who has autism, participated in the District 75 Program and learned to travel alone on public transportation from his home to school, both in the borough of Bronx, New York. This year Elliot has learned to travel to a neighboring borough, Manhattan, to his new high school. According to his mother, Julie, the travel training team was very supportive and worked to build on Elliot's strengths: "They never saw my son's autism as a barrier. When he made mistakes, like missing his stop on the bus or subway, or getting



Students in the District 75 Travel Training Program make their own Travel Booklets using photos and other images to help them reinforce landmarks and directions on their way to school, home, or other activities.

WHAT YOU SHOULD KNOW ABOUT YOUR TRAVEL TRAINING PROGRAM

When investigating travel training programs, one should review the training procedures each program offers or look over the training provided by your child's school. Although a national movement to establish travel training standards is underway, no standards presently exist. To determine the quality of the program available, you might want to ask some of the following questions.

*What kind of training have the travel trainers had?
*Does the travel trainer have experience working with students who have the same or similar disabilities and needs as your son or daughter?
*Who supervises the travel trainer?
*What are the safety policies for this program, and what safety skills are taught to the student?
*How does the travel trainer communicate with the school and with the family? How often?
*Are students' records maintained in a professional and confidential manner, in conformity with the IEP (Individualized Education Plan) requirements?
*How much time is spent with travel training in the classroom? How much time in actual travel?
*How is student progress evaluated, and what are the criteria for independent travel?
*Can you be put in touch with someone who has completed this training program?

Reprinted courtesy of National Information Center for Children and Youth with Disabilities (NICHCY) from their publication "TRAVEL TRAINING FOR YOUTH WITH DISABILITIES." For copies, contact NICHCY at (800) 695-0285 (Voice/TT) or visit their Web site: http://www.nichcy.org.

off at the wrong one, they showed him how to problem solve and deal with these situations. They taught him the responsibility of independence, the self-reliance to handle himself on the street with confidence." The ability to read, tell time, and do math are not mandatory for independent travel, and no individual should be denied training if lacking these skills. A good travel training program makes use of a student's abilities, while taking into account his or her disabilities.

Students are given the opportunity to generalize skills by traveling alternate routes during the instructional program. The instructional program concludes with a post-assessment of the student's travel skills using a "following" procedure. This is conducted by having a travel trainer who is not known to the individual follow close enough to ensure the student's safety while assessing the performance of travel skills when the student believes he or she is traveling alone.

The "following" procedure is a critical part of the success of the training program. Mrs. Sarlo agrees, "The travel trainers shadowed Elliot to and from school, and tested him by coming up to him in the street, asking him for money or personal questions. These things are so important to his learning how to handle the City on his own."

At the conclusion of the instructional phase of program, the "following" procedure provides the basis for written recommendations, documenting the student's ability to travel safely and independently. The recommendations are then given to the student, the family, and the school.

Student progress is communicated to the parents daily. For travel instruction to be effective there needs to be respect and trust between the travel trainer and the family. Parents need to be assured that there will be no recommendation for independent travel if there is a question of student safety.

Daily communication helps build that trust and prepare parents for the day when the instructional program is over and their son or daughter will be traveling independently. Based on the

continued on page 30

On His Way To A Brighter Future

Michael is an inquisitive boy with mental retardation. His behavior kept him from making progress in public school. His frequent hitting, biting, and noncompliance pulled him further and further behind, and no one knew how to get him back on course.

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Patterns began to emerge. Michael's toughest challenges, it turned out, lay in making transitions between tasks, so we provided him with structure and predictability. He was a boy of many hobbies, so we reinforced appropriate behaviors with rewards that reflected his personal interests. He had fallen into a cycle of frustration that tended to snowball out of control, so we taught him practical strategies dealing constructively with his anger.

Now, just over a year later, Michael is realizing a fuller potential. He's happier. His frequency of problem behaviors has dropped from 85 percent to nearly zero. He's returned to public school – and is once again moving forward with his life.

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Circle #21

IDEA and Travel Training

Recognizing the importance of self-directed travel, Congress addressed the issue of travel instruction in the reauthorization of the Individuals with Disabilities Education Act (IDEA) of 1997 and the Rehabilitation Act of 1998. Travel training, which is now a part of the amended IDEA's definition of special education, differs from orientation and mobility services, which are related services under the IDEA.

In IDEA '97, travel training was included in the amended definition of special education. The nation's public schools now are required to provide travel training "to children with significant cognitive disabilities, and any other children with disabilities who require this instruction, to enable them to -

(i) Develop an awareness of the environment in which they live; and

(ii) Learn the skills necessary to move effectively and safely from place to place within that environment (e.g., in school, in the home, at work, and in the community)."

Likewise, the Rehabilitation Act Amendments of 1998 also recognized the importance of learning to travel and to use public transportation in getting and keeping a job. The law requires vocational rehabilitation agencies and independent living centers to make travel instruction available to their consumers needing this service. This means that children receiving special education services will have the opportunity to receive instruction in basic mobility and independent travel skills, and the use of public transportation where appropriate, as part of their education programs.

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results that her son achieved through the District 75 Program, Julie Sarlo credits travel training and the responsiveness of the trainers: "He now walks taller, has more confidence, has more freedom, and has made us all proud. For each gain Elliot makes I feel like another door opens for him. The travel team provided him with a very special door, one that has opened on a world of possibilities."

Who are qualified providers of travel instruction?

The trainers are paraprofessionals, who have received extensive training in practices, procedures, and strategies necessary for teaching students with disabilities to travel on public transportation. These paraprofessionals are supervised by travel training teachers.

The competencies and standard for travel training professionals can be found in the monograph, "Travel Instruction for People with Disabilities: A Standards and Curriculum Development Project (1998)" available from Project ACTION and at the following URL: http://www.wmich.edu/hhs/blrh/html/blrh.htm. Currently, travel instruction personnel receive pre-service training in the identified competencies at a school or adult service agency before being considered qualified. It is expected that personnel preparation will be developed at the university- and college-affiliated programs in the future. **EP**

Margaret M. Groce is the Supervisor of the Travel Training Program, District 75. In the New York City Board of Education, special schools for students with moderate, severe, and profound disabilities are administered by the District 75 Superintendent. The Travel Training Program of District 75 provides travel instruction to students with disabilities other than blindness or visual impairments. Since 1970, approximately 9,000 students have received one-to-one travel instruction, and 86 percent successfully became independent users of public transit. The majority of the students had significant cognitive impairments and would be classified as having moderate mental retardation.

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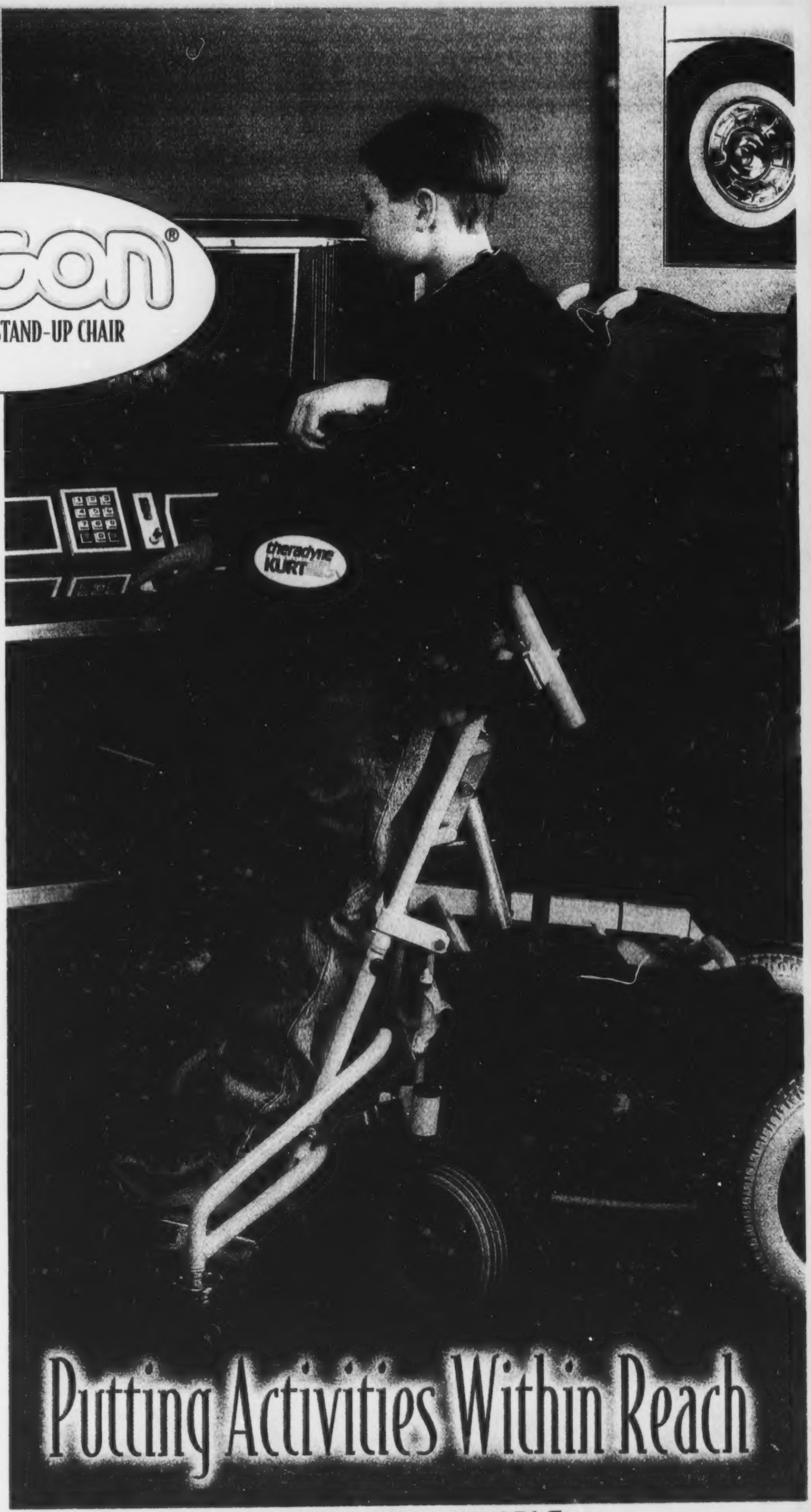

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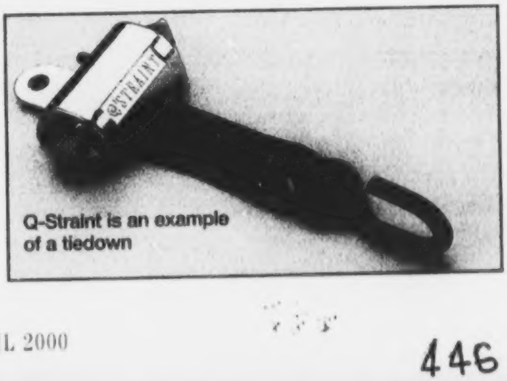
NEW DEVELOPMENTS IN SAFER TRANSPORTATION

FOR WHEELCHAIR USERS

Lawrence W. Schneider, PhD

Not too many years ago, it was common practice for students with physical disabilities to travel "sideways" in school buses and other van-type vehicles. The students were seated in their wheelchairs, which were positioned with backs up to the bus wall facing the aisle or center of the vehicle. The wheelchair was often "secured" during vehicle travel using bungy cords, belts, or pins through the wheel rims. The wheelchair occupant was usually restrained by horizontal belts placed around the abdomen or chest, but in many cases no restraint was provided. Little or no consideration was given to providing a measure of occupant protection in the event of a vehicle crash.

It is now widely recognized that facing wheelchair-seated occupants sideways in a vehicle is the least safe direction in the event of a frontal crash. It is also widely accepted that wheelchair-seated occupants should face forward in the vehicle, as do all other school bus passengers. In 1993, Federal Motor Vehicle Safety Standard 222 was amended to require installation of forward-facing wheelchair securement stations in original-equipment manufactured buses. In 1996, SAE Recommended Practice J2249, entitled "Wheelchair Tiedowns and Occupant Restraint Systems (WTORS) for Use in Motor Vehicles," was completed, and today there are many WTORS in use today that have been designed and tested to comply with this Recommended Practice.



Q-Straint is an example of a tiedown

SAE J2249 specifies numerous design and performance requirements for WTORS. The most important requirement, however, is that the wheelchair tiedown and occupant restraint system demonstrate effective performance when dynamically loaded by a 187-lb test wheelchair and a 170-lb adult crash dummy in a 30-mph, 20-g frontal impact test. SAE J2249 allows the use of any type of wheelchair tiedown that can effectively secure the test wheelchair in this test, but it requires that a belt-type occupant restraint with both upper and lower torso belts be provided (e.g., a three-point lap/shoulder belt or a four-point harness).

Wheelchair tiedowns

A docking-type wheelchair tiedown is one in which components on the wheelchair engage and lock with vehicle-mounted components. It is quick and easy to use, but these systems are generally quite expensive and are currently only suitable in situations where a single wheelchair user will be traveling in the vehicle (e.g., in a family vehicle). Docking systems also require the addition of components to the wheelchair frame to provide for engagement with the vehicle securement system.

The most effective wheelchair securement system that can be used with a wide range of wheelchairs is the four-point, strap-type tiedown system. A typical four-point strap-type tiedown consists of four adjustable-length straps that attach to the wheelchair at four securement points. The straps have floor anchors that insert into anchor tracks or other floor-mounted brackets. Examples of WTORS that have been successfully tested to SAE J2249 and that utilize a four-point tiedown with a three-point (lap and shoulder) belt occupant restraint include systems by Q'Straint, Kinedyne, Orthosafe, and Ancra.

The many commercially available four-point, strap-type tiedown systems now being used for forward-facing wheelchairs and occupants have significantly improved the safe transportation of wheelchair-seated passengers. However, until recently, an important part of effective occupant-protection systems remained a major problem in providing for safe transportation for wheelchair users. This part of the problem is that wheelchairs have not been designed for use as a seat in motor vehicles and, most important, they have not been designed to provide for easy and effective securement and occupant support in a crash situation.

Wheelchair crashworthiness

The wheelchair problem has recently been addressed by the development of a new ANSI/RESNA standard for "Wheelchairs Used as Seats in Motor Vehicles." This standard was developed by the Subcommittee on Wheelchairs and Transportation of the ANSI/RESNA Wheelchair Standards Committee.

The new standard called ANSI/RESNA WC/19 or 'WC/19" is expected to be approved and published in the spring of this year. It specifies design and performance requirements for "transit" wheelchairs, or wheelchairs that include a transit option. It also specifies information about the wheelchair that the manufacturer must include in presale literature and user documentation, as well as labels that must be permanently placed on the wheelchair indicating compliance with WC/19.

One of the most important requirements of this standard is that a WC/19, or transit wheelchair, must provide four, easily accessible attachment points to which four strap-type tiedowns can be connected for effective wheelchair securement. These securement points must comply with the specific geometry and location requirements to enable quick attachment of hook-type tiedown end fittings, or attachment of tiedown strap webbing, and must demonstrate sufficient dynamic strength to effectively secure the wheelchair in a 30-mph, 20-g frontal impact.

The primary drawbacks to the four-point tiedown system are that it is somewhat time consuming and difficult to use. However, by requiring securement-point geometry that allows for attachment by hook-type end fittings, the standard not only addresses improved crashworthiness of the wheelchair frame and seat, but it addresses improved ease of wheelchair securement using this very effective and universal system.

Occupant restraints

The new standard also addresses improvements in occupant restraint for wheelchair-seated occupants in two ways. Within the next two years, manufacturers of a WC/19 transit wheelchair must have their wheelchair pass tests using a wheelchair-anchored pelvic belt that will connect to a vehicle-anchored shoulder belt.

In addition, the standard requires that a wheelchair be rated with regard to its ability to accommodate the use of a vehicle-anchored, three-point belt system. This rating includes assessment of how easy it is to place a vehicle-anchored belt restraint on the wheelchair occupant, location and angles of the lap and shoulder belt on the user's body, and proximity of belt webbing to sharp edges on the wheelchair that could damage or cut the restraint webbing material. The results of this rating (A = excellent, B = good, C = fair, or D = poor) must be disclosed in the manufacturer's presale literature so that prospective buyers are aware of whether vehicle-anchored restraints can be easily and effectively used.

A guideline document to ANSI/RESNA WC/19 will be available in a few months and is available now for SAE J2249 on the Web site of the University of Pittsburgh Rehabilitation Engineering Center: http://www.rerc.upmc.edu/STDsDev/stdsindex.html. These guideline documents explain the rationale behind each of the requirements of these standards and clarify the purpose of each requirement. (See Resources box.)

What's ahead

It is important to note that many wheelchair and WTORS manufacturers, along with researchers and consumers, have been active participants in the development of these new standards. Also, many wheelchair manufacturers, and all of the major wheelchair companies, are now designing and testing many of their product models for compliance to the new transit wheelchair standard. As a result, motor-vehicle transportation for people in wheelchairs should be a lot safer and a lot easier in the years ahead.

There are still many issues yet to deal with concerning the safe transportation of students and adults in wheelchairs, but most of the primary issues have been addressed in these new voluntary standards. It is now up to consumers and transit providers to encourage the purchase and use of transit wheelchairs and J2249-compliant WTORS, and to ask manufacturers for evidence that their products comply with the new standards. **EP**

Lawrence W. Schneider, PhD, is a senior research scientist and Head of the Biosciences Division at the University of Michigan Transportation Research Institute.

Resources

To purchase a copy of SAE J2249, Wheelchair Tiedown and Occupant Restraint Systems for Use in Motor Vehicles, contact:

Society of Automotive Engineers, Inc.
400 Commonwealth Dr.
Warrendale, PA. 15096-0001
724 776-4970;
Fax: 724 776-0790
Web site: http://www.sae.org

To purchase a copy of Section 19 of ANSI/RESNA WC/Vol. 1, Wheelchairs Used as Seats in Motor Vehicles (expected to be available in April or May, 2000), contact:

Terry Reamer
RESNA
1700 N. Moore St., Ste. 1540
Arlington, VA 22209
(703) 524-6686
Fax: 703) 524-6630
E-mail: treamer@resna.org

Left, and below: Jim Jeffreys in the basketball game held at William Paterson University on November 8, 1999. *Photo by Craig Phillips.*

Try Doing It Sitting Down

by Denise Stone, PhD

I first met Jim Jeffreys, a talented graphics artist who is working on his Masters degree in photography, in the computer lab at William Paterson University in Wayne, New Jersey. I could not miss noticing that Jim's computer chair was actually a wheelchair. Low to the ground with a single front wheel, the chair looked very unique. As an assistant professor in the special education teacher training program at WPU, I was very interested and asked him if his chair was for a special purpose. Jim, who has no legs or hips, quietly told me that he was a wheelchair athlete and had crafted this athletic style chair in his garage, using spare parts from old wheelchairs.

We continued to talk and I learned a great deal—about accessibility, responsibility, and human potential.

"Resident Geek"

Jim shared with me his concerns about accessibility on the campus. He pointed out that many campus buildings were only minimally accessible, and even the new campus changes took students way out of the ordinary path. Over the past few months, he had been working with the University's ADA officer, Janet Barone Desenza, assessing the campus' wheelchair accessibility. "Janet listens," says Jim. Though more still needs to be done, the new accessible doors and elevator that were installed as a result of their assessment, have made an impact.

Jim also mentioned to me how most students have never said anything to him about his wheelchair. Showing his wry sense of humor, Jim said he had thought at times of going around wearing a T-shirt reading "Resident Geek," to bring attention to the issues of disability and accessibility. He hit upon the idea of having the University host a wheelchair basketball game in which campus students would compete against wheelchair athletes and, as Jim said, "try doing it sitting down."

He talked about the importance of issues of diversity, acceptance of differences, highlighting potentials and accessibility. He convinced me that this basketball game would be a meaningful event for the students on our campus. Anyone who meets Jim realizes the message he has gotten from the

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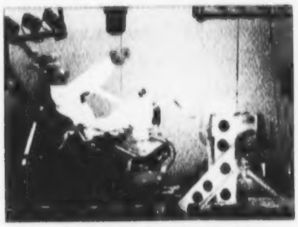

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Jim and his brother, Mark Jeffreys, with an acrylic painting done by Jim on display at William Paterson University, 1991.

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people in his life is not to accept a "no" or "can't." There is always a way to accomplish your goals.

In the process of planning the game, I asked Jim about his life. He related a story that has altered my life and those of the many other William Paterson University students who have come to know him.

Coming home

Thirty-two years ago, Jim was born to a South Korean mother who was pregnant by an American soldier. It was a difficult pregnancy, and she took medication, possibly thalidomide, to help her through. The son she gave birth to, whom she named Kim Byung Chul, had a congenital birth defect, phocomelia, which left him without a pelvis or legs.

Though her culture would not have disapproved if the boy's mother had let him die, she instead gave him up for adoption at Holt International Orphanage in Korea. Jim fondly recalls one of his nurses, Sung Lee, who learned how to care for his unique disability, yet let him develop his independence.

At age 4, Kim was adopted, sight unseen, by James R. and Harriet Jeffreys of Nutley, New Jersey, and his name was changed to James Elwood Jeffreys. The couple had two children, a daughter and a son, and though both Mr. Jeffreys and his son faced the challenge of having osteogenesis imperfecta, (a brittle bone disease, see "Ask the Doctor," page 94) Mr. and Mrs. Jeffreys shared a deep faith and a commitment that led them to open their hearts to other children without a family. Besides Jim, the Jeffreys family would grow to include five more children by adoption and one foster child. All five boys in the family have some type of disability. Harriet Jeffreys explains simply, "The children needed a home. They're all unique, and they're all family." Being part of this remarkable family would help shape Jim's future.

The Jeffreys family in Jim's early years. Jim is on Harriet Jeffreys' lap. James Jeffreys, Sr., is seated at right.

"Do what you can with what you have"

Jim describes his father as a "go-getter." Mr. Jeffreys, who used a wheelchair, was a cabinetmaker by trade as well as a stock car and speedboat racer. He showed his children through example that nothing should limit their dreams. "Each child had the opportunity to pursue whatever he or she wanted," explains Mrs. Jeffreys. "No child was ever offered more than the others." Mrs. Jeffreys served as a missionary in Nigeria in the 1950s and has had a career as a registered nurse. Of his mother, Jim says, "I have great respect for her. She is a person who could accomplish anything." He remembers that from early on, he was encouraged to be independent. When he started kindergarten, he had just gotten a new set of prosthetic legs and a set of "Canadian," or forearm, crutches. "The school had stairs leading to the entrance, and the principal offered to carry me," Jim recalls. "My mother said, 'No, he has to learn to walk.'" He jokes, "At that age, I would rather have been carried!"

The Jeffreys made no excuses for any of their children. Growing up, each of them had to do chores around the house and were made fully aware of their importance as individuals with something to offer the world. Their parents made a point of accentuating the positive. "You have to be happy with yourself," Mrs. Jeffreys points out, emphasizing the motto they taught their children was: "Do what you can with what you have." Encouraging their children to do as much as possible is a bit of advice Mrs. Jeffreys shares with other parents, saying "Don't tell them they can't do something when they can."

When Jim reached high school, however, he faced a difficult choice regarding his independence. The high school was larger and the halls filled with too many students to safely navigate on his prosthetic legs. He could easily be knocked down and injured. Jim decided to give up the legs for a wheelchair.

Shooting for the stars

It was then that Jim's dad put up a basketball hoop in the back yard. Though Jim was very small at the time and could not reach the net, his dad persisted. "He told me that he was not going to let me be a couch potato, and that I should get involved in wheelchair sports," Jim recalls.

He started playing and later joined the Parsippany, New Jersey, Elks Wheelers Basketball Team. Jim considers Mike Lione, his coach, to be one of the great influences in his life, challenging him to try harder. "Mike pushed me beyond my limits, beyond where I thought I could go," says Jim. Mike has remained his coach, mentor, and friend for the past 20 years and he also got Jim "hooked" on basketball.

Hoop dreams

Planning Jim's dream basketball game grew to become a concerted effort involving the University student government and associations such as the Student Council for Exceptional Children. Though they had never met Jim, the students felt the importance of his message and were motivated by his determination. The marketing manager of the New Jersey Nets basketball team was also contacted, and the team generously donated a signed basketball to raffle off. It was decided that profits from ticket sales and the raffle would be donated to the Paterson Unified Sports Program, a local group that provides children

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A program for teens which will allow them to experience supervised, independent travel.

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A week-long sleep away camp experience for children/adolescents with physical disabilities.

CAMPOREE/UNDER THE UMBRELLA:
Arts, crafts, sports, cooperative games, music, and special activities for children who have physical disabilities, PDD (autism) or AD/HD.

CAMP CHATTERBOX:
An overnight, intensive therapy camp for non-speaking children and adolescents who use augmentative and alternative communication systems and a training program for their parents.

MOVERS AND SHAKERS:
A sensory motor group program of occupational, physical, and speech therapy activities for children with developmental delays.

CHAT AND SNACK:
An oral motor, group program of exercises to strengthen and improve movements for talking and eating.

KUNG FU/KARATE:
Martial arts instruction for children with AD/HD, cerebral palsy, or any diagnosis causing gross motor or fine motor problems.

DEVELOPMENTAL DANCE:
A dance program for children with any diagnosis causing gross motor, fine motor, or social interaction delays.

READY, SET, SCHOOL:
A program to enhance pre-writing skills for children with fine motor difficulties.

PALS PARADISE:
Creative arts, drama, martial arts, and crafts for children with physical or developmental disabilities.

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A program for children and adolescents with physical disabilities or movement dysfunction.

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Circle # 54

ROLE MODELS

Jim and students (l-r): Michelle Dorn, Dan Curcio, and Lauren Levine who were instrumental in helping Jim plan the basketball game fundraiser. *Photo by Craig Phillips.*

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with and without disabilities an opportunity to participate in athletics together. The game was growing even greater in significance, and its benefit would now be felt in the local as well as the University communities. No one was prepared, however, for it to take on a much deeper meaning.

Last fall, while plans for the basketball game were underway, Jim's father passed away. The feeling of the students was all the same. They had never met James R. Jeffreys, but they had respect and awe for the man who overcame his own disability to provide a wonderful home for nine children. The children, now grown and each with a job and pursuing his or her goals, returned home to pay their respects. "They were encouraged to do whatever they wanted to do despite their limitations," Mrs. Jeffreys notes with pride, "and they all did."

Postscript

When Jim came back to school, I suggested we make the game a tribute to his dad. Jim said, "That would make my dad very proud." Jim's life has made a difference in many lives. The game was the symbol, the galvanizing event, but the message is to support each other in life as we "try doing it sitting down." **EP**

Dr. Denise Stone is an Assistant Professor of Education in the Department of Special Education and Counseling at William Paterson University.

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Johnny, 51 lbs. and 48" tall, in the Columbia Car Seat
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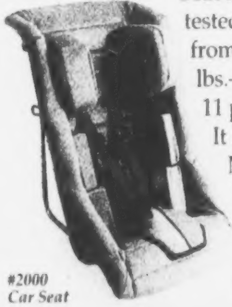

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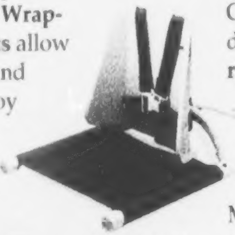
#8600 Medium Recliner for a child 40"-54" tall, up to 130 lbs.



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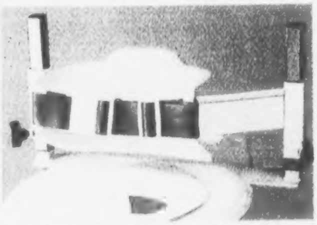

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Mobility-Equipment Exchange and Recycling for Users of Mobility Devices:

The "Back in Action" Program

by David Chamalian

As young children grow into adolescence and, eventually, young adulthood, their needs change, as do technology and the availability of a broader range of products. Mobility devices, such as walkers, standers, wheelchairs, etc., that were once useful become either too small, no longer suitable, or passed over for a different or newer device. With the help of equipment exchange programs, a conduit exists for these neglected devices to be placed in the hands of people who need them.

Meghan Voit, Project Manager (left), and Dan O'Neill, Director of Back in Action, inventory the equipment available through the used assistive device recycling center at Matheny School and Hospital in Peapack, NJ.

Back in Action

Back in Action is New Jersey's statewide equipment exchange program. (Many states have assistive technology projects which operate a similar equipment exchange program—see editor's note.) This nonprofit program essentially serves as a "matchmaker"—bringing together potential buyers and sellers of used mobility and assistive technology devices, such as wheelchairs (both power and manual), walkers, canes, standers, scooters, adapted vehicles, stairlifts, computers, electronic communication devices, etc. The Program Coordinator of Back in Action, Kenneth Robey, PhD, explains that the program serves a very practical function. "Countless wheelchairs, crutches, adapted computers, and other devices are sitting in basements and garages because they are no longer needed by whoever purchased them. Recycling programs like Back in Action," he continues, "help to get those devices to the people who need them."

POTENTIAL BUYERS NEED ONLY CALL THE TOLL-FREE NUMBER IN THE CATALOG TO BE "MATCHED" WITH THE PERSON SELLING THE ITEM.

Equipment exchange is easy

Back in Action's catalog lists, free of charge, all products that are for sale, including a description of the product. There is also a section in the catalog dedicated to items requested. Potential buyers need only call the toll-free number in the catalog to be "matched" with the person selling the item. (Sellers retain possession of the item until sold.) Contact information will then be furnished, and the transaction will proceed privately between the buyer and seller. Back in Action serves only as the initial go-between.

Recycle your used mobility devices

Back in Action also accepts donations of mobility and assistive technology devices. All donated equipment is evaluated, cleaned, repaired or restored (if necessary). It is either advertised for sale in the catalog for only the cost of the refurbishment, made available for loan, or given to someone who needs it. Says Dr. Robey, "The recycling of used assistive devices benefits everyone involved: the person who needs assistive technology but cannot access it through other means; the person who has valuable equipment but no longer needs it; and the taxpayer whose tax dollars are not being spent on the purchase of expensive equipment." Since insurers have prohibitive rules on reimbursing for certain items, programs like Back in Action help make used and re-conditioned equipment affordable.

EDITOR'S NOTE: Back in Action in New Jersey is one of 44 state assistive technology programs in the country that operate equipment exchange/ loan services. The program is administered by the Matheny School and Hospital in New Jersey under the auspices of the Rehabilitation Engineering and Assistive Technology Society of North America (RESNA) and its Technical Assistance Project. RESNA is an interdisciplinary association of people with a common interest in technology and disability. **EP**

To contact **Back in Action** or to order a catalog, call Meghan Voit, Project Manager, at (800) 554-2626; or log onto their Web site: http://www.matheny.org/backinaction. To find out if your state has a similar equipment exchange/loan program, see the State Assistive Technology Programs directory in EP's Annual Resource Guide 2000 (pages 100-101) for listings of each state's Technical Assistance Project; or contact the RESNA Technical Assistance Project at (713) 524-6686; (703) 524-6639 (TTY); E-mail: resnata@resna.org; Web site: http://www.resna.org/hometa1.htm.

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Circle #50

STAND AND DELIVER: A Guide to Self-Propelled Standers

By Ginny Paleg, PT and Steve Mauricio, PT

Standers at a glance

Product	**Rabbit** by Snug Seat	**Axiom Wheelies** by Prime Engineering	**Wheelstands** by DavisMade
Web site	http://www.snugseat.com	http://www.primeng.com	http://www.standingdani.com
Strengths (+)	+painted spoke covers, push handle, footplates adjust independently of one another and in all directions	+great hot pink color lots of room for growth and good brakes	+can snap in and out of wheelchair base, unique bike seat system, wheels adjust forward and backward, can be customized to accommodate even the most severe orthopedic deformities
Weaknesses (–)	–may not be wide enough for kids in spica casts	–need an allen wrench to adjust	–single user only
Does the person need to be lifted in and out?	no	no	yes
Easily adjustable for multiple users?	yes	no	no
Does it collapse easily and fit into a car?	no	no	yes
Customizable to accommodate orthopedic deformities?	no	no	yes
Cost without accessories	$1625	$1275-$1595	$3250-$3850
Wheel sizes	20"-26"	20"-34"	20"-35"
User's height range	32"-50"	30"-60"	26"-64"
Cambered wheels	yes	yes	yes
Wheels come off for storage	yes	yes	yes
Can use without wheels	no	no	no
Different sizes available	no	yes	yes
Comes with tray	tray and basket available	available	available
Singular height adjustments foot plates	yes	yes	yes, in all planes
Lateral supports adjust indepently	yes	yes	yes
Child can access brakes	no	no	yes
Has both push rims and spoke guards	yes	yes	pushrims only
Uses knobs for adjustments	yes	no, needs tools	no, needs tools
Angle adjustable (prone and supine)	yes	yes	yes
Can add head support	yes	yes	yes
Telephone numbers	(800) 336-7684	(800) 82STAND	(810) 742-0581

This chart is meant as a guide for families and professionals to assist them in determining if a self-propelled stander is appropriate and which model offers the options that they need. Equipment changes all the time, so please check with your equipment supplier to make sure that the information below is still accurate.

continued on page 46

Easy Stand Magician and Easy Stand 5000 with Mobile Option by AltimateMedical	**Mobile prone stander** by Tumbleforms (Sammons Preston)	**Abler** by Jennie Company	**Wheelabout** by Mulholland
http://www.easystand.com		http://www.jenniecompany.com	http://www.dis-abilities.com/mulholland.htm
+easy placement for larger person, multiple knee pad placements can be used as a desk and stander.	+neoprene sling system is comfortable	+can be tilted 180 degrees to allow supine positioning	+can be angled fully prone or supine and even used for postural drainage
–need an allen wrench for some adjustments and need good upper extremity strength to propel	–middle strap may be too short for many waists	–Wheels can be difficult to reach for a child with short stature or below average height. Tools needed to make adjustments.	–person is very high off the ground
yes	no	no	no
yes	yes	yes	yes
no	no	the wheels can be removed making the small unit fit into most any car. The medium and large units require a large vehicle to hold the frames.	no, but can be taken apart into 3 pieces
no	no	no	yes
$2485 for Mobile Magician and $3280 for 5000	$1,050	$835-$1495	$1582-$2951
4" and 11" casters	N/A	20", 26", and 35"	24"-30"
32"-77"	30"-37"	24"-60"	29"-68"
no	yes	yes	yes
no	yes	yes	yes
Easystand Magician cannot, but 5000 is available as a modular	no	yes	yes
yes	no	yes	yes
standard on Magician and available on 500 series	no	available	yes
no	no	no	yes, in all planes
yes, available as accessory	yes	yes, available as accessory	yes
push rim locks accessible, caster locks are not	no	no	yes
pushrims only	neither	neither	pushrims only
yes	yes	yes	yes
adjusts from sitting to standing	no	yes	yes
yes	no	yes	yes
(800) 342-8968	(800) 323-5547 (call to request Tumbleforms catalog)	(888) 851-4377	(800) 543-4769

continued from page 45

What are self-propelled standers?

These devices are standers that children can push by themselves. Also called "mobile prone" or "dynamic" standers, they allow children the benefits of standing with the opportunity to explore their environment, strengthen accessory breathing muscles, upper trunk musculature and upper extremities, as well as to improve head control.

In the past, children with gross motor dysfunction have been placed in stationary standers—stuck in one place with no room or chance to move around. This is called "static" standing and occurs when the child is passively supported in the upright position and does nothing to actively maintain this position by him or herself.

The latest research shows that "dynamic" standing may be better than "static" standing. Dynamic standing occurs when the individual is free to practice balancing and changing positions, as well as flex and extend the ankles, knees, and hips. It just makes sense that active is better than passive. Dynamic Systems and Motor Control/Learning Theories would all support this idea.

Luckily, practice and theory have caught up with each other and the means of providing the opportunity for dynamic standing is readily available through the use of self-propelled standers. With these devices, a child can practice dynamic standing with the freedom to move both within the constraints of the device to propel it around the room or building. Many companies are marketing these devices. We have defined this line of products as all upright standers that have the option of being propelled using both hands and/or arms. Powered systems have not been addressed.

Who are they for?

Self-propelled standers are appropriate for anyone who can tolerate being placed upright (try the Wheelabout, Rabbit or Standing Dani if they cannot) and has even the most remote potential to push the wheels. All of these standers have their large wheels placed high up in front of the individual to make pushing much easier. Children who are too weak to push their wheelchair when the wheel rims are placed below and behind their bodies, can easily move the wheels on these standers.

We have worked with kids who had little to no use of their arms and hands who began learning about movement using hand-over-hand guidance from an adult or sibling. If a child has little to no voluntary movement in his or her hands but has a "startle" reaction, this response can be used, and sometimes it can be shaped over time into a voluntary action. This can be done by placing the child's hands on the stander's wheelrims and then in some way eliciting the startle response (i.e such as by clapping or touching the child). If the child reacts by pushing his or her arms away from their bodies, the wheels will move.

From this, the child discovers that "If I move a part of my body then my entire body moves through space." What a wonderful cause and effect experience! This movement will stimulate the body's balance response, and a whole slew of sensory information will be processed. In many children with severe disabilities, this one lesson in cause and effect may be one of the richest educational experiences we can offer. Children learn that they can move and can have an impact on their body, their environment, and their world. This simple lesson may form the basis of switch toy use, powered mobility, and/or augmentative communication.

What benefits have we seen?

- Increased passive range of motion of hamstrings and hip flexors
- Clearer breathing
- Increased vocalizations
- Increased upper extremity use

Who had trouble using this equipment?

- People with severe hypotonia (floppy muscles)
- People with severe opisthotonus (extensive arching)
- People with hemiplegia (weakness on one side of the body.) If the individual can only push with one hand, it causes the device to go around in circles)

What's missing from almost all the products?

- One arm drive
- Fancy (cool colors/patterns) and two sided spoke covers (except Rabbit)
- Cogs to push
- Fully adjustable foot plates (except Standing Dani, Rabbit and Mulholland)
- Optional ventilator tray (except Standing Dani)

Other benefits

In our experience, many children and adults with even the most severe gross motor dysfunction, can learn to push these devices short distances in six to nine months. Self-propelled standers may also be used to teach head control. We have used these products for children that have little or no head control (the exceptions are if they have tracheotomies, wakeful apnea, or other breathing problems).

Self-propelled standers offer a new way to help kids with gross motor dysfunction and developmental delays to improve in their control over posture, strength, range of motion, and understanding of how their bodies interact with their surroundings. For children who have tight hamstrings, heelcords or hip flexors and need prolonged stretching, self-propelled standers offer and excellent option.

These devices also benefit children who cannot yet stand independently or have poor trunk control. This can be achieved by simply lowering the trunk support as much as is safely possible and encouraging the child to use trunk muscles by leaning, weight shifting, and pushing the wheels. Last but not least, another important benefit of self-propelled standers over traditional stationary standers, is that they can provide opportunities for interaction and FUN! **EP**

Ginny Paleg, PT, is a pediatric physical therapist at The Hospital for Sick Children, Washington, DC. Steve Mauricio, PT, is a pediatric physical therapist who is in private practice at Huntington Rehab, Fall River, MA.

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Circle #63

GOING MOBILE

TWO PUBLICATIONS PROVIDE INFORMATION ON ADAPTIVE TRANSPORTATION

Following is excerpted material from two sources that provide practical, step-by-step information on how to choose and successfully adapt a vehicle for transporting a person with a disability.

The US Department of Transportation has recently published a brochure entitled "Adapting Motor Vehicles for People with Disabilities." The information in this brochure is a general overview on preparing yourself and mapping out your strategy for choosing the right vehicle and having it adapted. It is based on the research and experience of driver rehabilitation specialists and other individuals who work to facilitate the adaptation of motor vehicles for people with disabilities. Rhonda Dinello, program analyst for the Consumer Automotive Safety Information Division of the National Highway Traffic Safety Administration says, "This brochure contains information that guides parents through a proven process for adapting motor vehicles—to ensure their children's safety and to optimize mobility. It is a practical guide based on government engineer studies put into plain English."

The accompanying side bar, "Tips to Remember When Choosing Adaptive Vans and Adaptive Wheelchair Carriers," details the search for the proper vehicle and its adaptation. The excerpt is adapted from a book by Becky Plank, executive director of the National Mobility Equipment Dealers Association. To order the book, write to Becky's Treasures, Inc., 909 E. Skagway Ave., Tampa, FL 33604-1747.

WHERE TO BEGIN

Evaluate your needs

Driver rehabilitation specialists perform comprehensive evaluations to identify the adaptive equipment most suited to your needs. Upon completion of an evaluation, you should receive a report containing specific recommendations on driving requirements or restrictions, and a complete list of recommended vehicle modifications.

Finding a qualified evaluator

To find a qualified evaluator in your area, contact a local rehabilitation center or call the Association for Driver Rehabilitation Specialists (ADED). (See Resources section for contact information.) The Association maintains a data base of certified driver rehabilitation specialists throughout the country. Your insurance company may pay for the evaluation. Find out if you need a physician's prescription or other documentation to receive benefits.

Evaluating passengers with disabilities

Evaluators also consult on compatibility and transportation safety issues for passengers with disabilities. They assess the type of seating needed and the person's ability to exit and enter the vehicle. They provide advice on the purchase of modified vehicles and recommend appropriate wheelchair lifts or other equipment for a vehicle you own. If you have a child who requires a special type of safety seat, evaluators make sure the seat fits your child properly. They also make sure you can properly install the seat in your vehicle.

HOW TO DETERMINE IF YOU NEED A SPECIAL VEHICLE OR IF YOU CAN MODIFY AN EXISTING ONE

Select the right vehicle

Selecting a vehicle for modification requires collaboration among you, your evaluator, and a qualified vehicle modification dealer. Although the purchase or lease of a vehicle is your responsibility, making sure the vehicle can be properly modified is the responsibility of the vehicle modification dealer. Therefore, take the time to consult with a qualified dealer and your evaluator before making your final purchase. It will save you time and money.

The following questions can help with vehicle selection. They can also help determine if you can modify a vehicle you own.

- Does the necessary adaptive equipment require a van, or will another passenger vehicle suffice?
- Can the vehicle accommodate the equipment that needs to be installed?
- Will there be enough space to accommodate your family or other passengers once the vehicle is modified?
- Is there adequate parking space at home and at work for the vehicle and for loading/unloading a wheelchair?
- Is there adequate parking space to maneuver if you use a walker?

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Vehicle evaluators can help you decide which modifications meet your needs.

Photos courtesy of Braun Corp. and Ricon Corp.

TIPS TO REMEMBER WHEN CHOOSING ADAPTIVE VANS AND ADAPTIVE WHEELCHAIR CARRIERS

Excerpted and
adapted from:

DISABLED DOESN'T MEAN IMMOBILE

Adaptive Aids for
Transportation
Matching Vehicle
Disability,
Vehicle and Equipment

by Becky Plank

Mobility is probably the most important privilege any human being has in today's world. Today, finally, we have the necessary technology to assist in converting vehicles for the physically challenged so they may exercise that privilege.

Nonetheless, adaptive-equipment dealers and driver-evaluators are rightly concerned that consumers are not aware of the products available to them. Consumers needs to know where to turn, and what steps to follow, when purchasing their vehicles and equipment.

If you have any questions about your vehicle and/or equipment, find an adaptive-equipment dealer and/or a driver evaluator/trainer. They can answer your questions, or will assist in finding a solution to your problem.

PURCHASING AND ADAPTING VANS

FULL-SIZE VANS

When choosing a van to transport a person with a disability, there are many details to keep in mind.

- One of the most important things to consider is the **engine cover**. (Editor's note: In full-size vans, the engine usually extends into the vehicle.)

1) How far does it extend into the vehicle?
2) Does the engine cover become an obstacle to easy transfer or swiveling?

Occasionally, people have suffered injury to their feet, ankles, and legs (in some cases even breaking a bone) because their feet got caught between the engine cover and the seat.

- Another part of the van to consider is the **height of head space**. Measure from the floor to the roof, and then determine your seated height, obtained by measuring from the floor to the top of the head when you are seated in a wheelchair.

If you plan to drive, or even just ride, from your wheelchair, you need enough room for movement.

- The necessary head space can come from a couple of options.
- One is **raising the roof**, i.e., cutting out the factory roof and adding a higher fiberglass top. There are several roof brands and models available, along with the cosmetics needed for an attractive van after the conversion.
- Your evaluator may prescribe a **lowered floor** for your van. That requires cutting out the floor's metal, lowering the floor itself, then welding back the metal.

Remember to have the new flooring undercoated if your dealer does not include it in his service. And, if you require a lowered floor, be certain your dealer has a certified welder on staff.

The number one consideration in purchasing a van when the floor must be lowered is the frame. It is highly recommended that the van have a frame and not a unitized body (where the body is the frame). Some dealers do build a frame for lowering the floor in a unitized body, but the expense is very high. Some dealers will not perform this procedure. This is another example of the need to consult with your dealer before purchasing a van.

- If you are purchasing a full-size van to use with a wheelchair lift, you need a long **wheelbase**, or extended body. This will give you ample room to maneuver your wheelchair when entering and exiting the van.
- Do not forget to measure the doors as well. If, for any reason, you cannot bend your head forward, you should ask your dealer about **raised doors**. These are doors in which a lift is installed.

Raised doors have an extra panel of metal welded to the top of each door. The top needed for raised doors is different. Thus, if you have your van converted but do not include the raised doors, all of the interior may need to be removed to install the proper top for raised doors—an unnecessary expense.

MINI-VANS

When choosing between purchasing or converting a mini-van, there are two alternatives:

- Have the dealer convert the vehicle locally. There are currently a number of products (i.e., lifts, raised tops, etc.) that will work when converting the mini-van.
- Order your vehicle from a manufacturer of mini-vans for the physically challenged.

If you decide to go this route, there are currently several models of mini-vans on the market for people with disabilities. These mini-vans have been attained from one of the automobile manufacturers, then literally taken apart for modification. Thus, you need to be certain the mini-van modifier is recognized by the automobile manufacturer so as to avoid factory warranty problems.

Getting in and out

The following are the two most important considerations when a wheelchair user is entering and exiting a mini-van:

- Head room inside the vehicle: See if you need a raised roof with the lowered floor; and
- Height of the doors: To enter and leave the van.

Most of the mini-vans on the market have a lowering device—an air bag below about the size of an old-fashioned oatmeal box—with an air compressor. They are also equipped with ramps, whether in the side or rear. These vans are small, as the name implies, which provides the convenience of a small vehicle, but limits the number of passengers you can transport. And, if you choose the rear entry ramp, keep in mind you will lose the rear sofa and center seats. You need to discuss this with your dealer and/or evaluator.

A **dual battery system** is available from the adaptive-equipment dealer. The purpose of a dual battery is to provide power, should there be a power failure in the main system. The reserve power will let you exit the van safely.

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Have wheelchair, will travel

Taking a wheelchair along in a van or car can be accomplished by using a carrier to lift it. Carriers store manual wheelchairs for the journey while the wheelchair user rides in the vehicle. Wheelchair carriers come in four basic styles:

1) The automatic car-top carrier.

The car-top carrier is an electric motor-driven hoist. A steel pin lowers, picks up a manual wheelchair, and the chair folds as it rises to the carrier. The carrier then closes. All the functions are operated by switches.

If your needs include a car-top carrier, it will be of utmost importance that an adaptive equipment dealer examine the car before the purchase.

Among the things he or she will be checking are:

a) The actual size of the roof—will the roof be able to accommodate the carrier?

b) The make of the carrier in which you are interested, (i.e., is it too heavy for the car model you have chosen?).

2) The bumper-mounted carrier.

A bumper-mounted wheelchair carrier for a manual wheelchair could get complicated if combined with a molded auto bumper. Occasionally the bumper-mounted installation requires the adaptive-equipment dealer to drill a couple of holes into the bumper. These can be plugged should you remove the carrier later. One more thing to consider is the accessibility of the trunk. Most of the bumper-mounted carriers can easily be removed to give access to the trunk.

3) The hitch-mounted carrier.

These carriers tilt down to load the wheelchair and easily tilt up and lock in place.

4) The pick-up carrier.

This carrier is for use on pickup trucks. The wheelchair will have to be folded, then the lift picks up the chair with an electric-driven motor and stores it in the bed of the truck.

TYPES OF WHEELCHAIR LIFTS AVAILABLE

Platform lifts

The platform lift stores either in the side, the rear, or under the floor of the van. The lift requires two doors, or the sliding door on the side of a van. The platforms have expanded metal in the upper half of the platform for better visibility when the lift is folded and the van is being driven. The fold-in-half platform folds to give better accessibility to the doors.

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Circle #17

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The under-the-floor lift requires modifications under the van to the exhaust system, gas tank, etc., depending upon the make of van. There are both solid and fold-in-half platforms. Some of the fold-in-half platform lifts are mounted on a single post.

Be aware of the difference between automatic and semi-automatic lifts. A fully automatic lift will fold, unfold, lower and raise by operating a switch, usually located on the dash, but in some cases, on the side of the lift. A semi-automatic lift requires manual folding and unfolding of the platform. A hand-held pendant switch mechanically lowers and raises the platform.

Rotary Lifts

Another lift is the rotary, sometimes called a "swing" lift. The platform never folds, it swings inside, outside, and up-and-down. The rotary lift swings into the van and the lift platform sits on the floor in the middle of the van.

Some individuals like the rotary lift because of the parking convenience. Less room is needed to enter or exit the van. Also, this lift is mounted on one post inside the van. The post controls the swinging action of the lift. One of the drawbacks to the rotary lift, though, is the cross-over bar. On some rotary lifts, this bar connects the platform to the swing bar, and limits space for loading and unloading on the platform.

Backup Systems

Switches operate the lifts as well as the power openers. In the event of a power failure, however, a backup system is necessary.

Many government agencies require a lift to have a backup system for use in emergencies. The lift then can be manually maneuvered and users can exit the van with assistance from an outsider. Most of the backup systems are too hard to operate alone, so expect to need someone's help.

Safety flaps

All lifts have an extension or "curb" at the edge of the platform which is approximately three to four inches high. This safety flap is designed specifically to prevent the wheelchair or scooter from rolling past the edge of the platform.

There are advantages and disadvantages associated with all lifts. No one lift fits the needs of every individual. It all depends on the individual's needs and wants. However, after reading this section you can be aware of what to look for when purchasing a lift that will accommodate your needs.

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- What additional options are necessary for the safe operation of the vehicle?

Choose a qualified dealer to modify your vehicle

Begin with a phone inquiry to find out about credentials, experience, and references. Ask questions about how they operate, such as:

- Do they work with evaluators?
- Do they require a prescription from a physician or other driver evaluation specialist?
- How long will it take before they can start work on your vehicle?
- Do they provide training on how to use the adaptive equipment?

If you are satisfied with the answers you receive, check references; then arrange to visit the dealer's facility. Additional questions you may want to ask are:

- Are they members of the National Mobility Equipment Dealers Association (NMEDA) or another organization that has vehicle conversion standards?
- What type of training has the staff received?
- What type of warranty do they provide on their work?
- Do they provide ongoing service and maintenance?
- Do they stock replacement parts?
- How much will the modification cost?
- Will they accept third party payment?
- How long will it take to modify the vehicle?
- Can the equipment be transferred to a new vehicle in the future?
- Will they need to modify existing safety features to install the adaptive equipment?

Vans can be purchased already adapted, or may be modified by an accredited dealer.

Training on the use of new equipment

Both new and experienced drivers need training on how to safely use new adaptive equipment. Your equipment dealer and evaluator should provide information and off-road instruction.

Cost saving opportunities

The costs associated with modifying a vehicle vary greatly. Therefore, whether you are modifying a vehicle you own or purchasing a new vehicle with adaptive equipment, it pays to investigate public and private opportunities for financial assistance. There are programs that help pay part or all of the cost of vehicle modification, depending on the cause and nature of the disability. For information, contact your state's Department of Vocational Rehabilitation or another agency that provides vocational services, and, if appropriate, the Department of Veterans Affairs (see the Resources section). Also, consider the following:

- Many nonprofit associations that advocate for individuals with disabilities have grant programs that help pay for adaptive devices.

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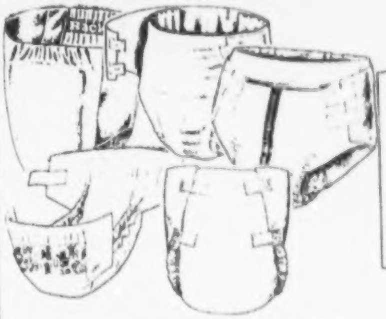

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- If you have private health insurance, you may be covered for adaptive devices and vehicle modification.
- Many manufacturers have rebate or reimbursement plans for modified vehicles (see Resources section).
- Some states waive sales tax for adaptive devices if you have a doctor's prescription for their use.
- You may be eligible for savings when submitting your federal income tax return. Check with a qualified tax consultant to find out if the cost of your adaptive devices will help you qualify for a medical deduction. **EP**

To order the brochure, contact the Auto Safety Hotline at (888) DASH-2-DOT; or visit the Department of Transportation's Web site at http//: www.nhtsa.dot.gov. For a complete list of van conversion dealers, see page 108.

RESOURCES

The following manufacturers offer rebates or reimbursements on new vehicle modification.

Daimler Chrysler Corporation
(800) 255-9877
TDD Users: (800) 922-3826

Ford Motor Company
(800) 952-2248
(TDD Users: (800) TDD-0312)
http://www.ford.com/showrooms

General Motors Corporation
(800) 323-9935
(TDD Users: (800) TDD-9935)

Saturn
(800) 553-6000, Prompt 3
(TDD Users: (800) 833-6000)

Volkswagen
(800) 822-8987
http://www.vw.com

Audi
(800) 822-2834
http://www.audiusa.com

ASSOCIATIONS

(These organizations can provide information on finding evaluators and funding for adaptive vehicles)

The Association for Driver Rehabilitation Specialists (ADED)
P.O. Box 49
Edgerton, Wisconsin 53534
(608) 884-8833
http://www.driver-ed.org

National Mobility Equipment Dealers Association (NMEDA)
909 E. Skagway Avenue
Tampa, Florida 33604
(800) 833-0427
http://www.nmeda.org

Automobile Association of America (AAA)
1000 AAA Drive
Heathrow, Florida 32746-5063
(404) 444-7961

Department of Veteran Affairs
(800) 827-1000

State Departments of Vocational Rehabilitation
Check state government listings in your local phone book.

ADAPTIVE RECREATION

Easy Riders

Adaptive biking makes it easier for people with disabilities to get out and on the road.

by Ryan Mayo

As the snow melts, cyclists everywhere are getting geared up for the upcoming warm weather. The outdoors are calling, and it is time to get behind the handle bars for another great summer of exercise and fun.

Biking for people with disabilities has seen a popularity surge in the past few years, and the technology to accompany it is astounding. In fact, adaptive cycling has an amazing array of possibilities for all kinds of disabilities, proving that it can be an incredible recreation opportunity for all.

"I think it helps a lot of people physically," says Stacey Parker, an instructor with the National Sports Center for the Disabled (NSCD) in Winter Park, Colorado. "Biking really works the major muscle groups, helping motor control and balance. It gets the blood flowing and helps people feel good about themselves emotionally as well."

Setting the wheels in motion

There are two main classes of bikes ideal for use by people with disabilities: tandem and hand-cranked (hand cycles). The tandem bikes are designed to have a "pilot," or driver, in the front seat, while a cyclist with a disability pedals in the back seat. This is ideal for children with a physical disability, visual impairment, head injury, or cognitive delay. Hand cycles are good for use by children with lower-body disabilities, including those involving spina bifida, multiple sclerosis, muscular dystrophy and cerebral palsy. It is important to find the right fit between the rider and bike.

A child with a below-the-knee amputation on a mountain bike enjoys the freedom of adaptive cycling.

Tandem biking requires a pilot to be seated in the front. Above, a teen who is blind takes a break with her pilot.

PHOTO BY KIEFEL SPORTFOLIO AND THE NATIONAL SPORTS CENTER FOR THE DISABLED

Both types of bikes are easily adaptable for different needs. On tandem bikes, "bear claw" pedal cages with straps can be attached to keep the rider's feet from sliding off the pedals. Hand cycle riders can put their hands in "cuff mittens," which are attached to the pedals to aid in gripping. Varying the shape of the pedals or handle bars for easier and better grip is also an option. Lap or chest belts can help tandem bike riders stay positioned in the saddle. If keeping balanced in the saddle is too difficult for the rider, however, a hand cycle is usually recommended. Velcro straps can be used to keep the legs in place on the hand cycle.

A bicycle built for two

Balance, trunk control and leg muscles come into play when riding on a tandem bicycle. Children work along with their pilot in front to achieve the bike's motion. It is a team commitment, and the two riders must work to communicate at all times to be successful.

"We use tandem bikes mostly for people who are blind and for those who don't feel comfortable using their arms," said NSCD instructor Tony Peters. "Balance control is important in tandem biking, but the student only has to focus on pedaling rather than steering. For beginners, we will have instructors who will walk or jog alongside the bike until the duo get the hang of riding together."

One of the great things about tandem bikes is that they are very versatile. The NSCD uses tandem mountain bikes with large, fat tires.

continued on page 56

continued from page 55

The bikes work well in all kinds of terrain, but the instructors will assess the skill and comfort level of the rider before jumping into anything new. "We look at the goals of the student to decide the type of terrain to ride on," Peters said. "We typically use flat, paved routes early on, moving on to more advanced mountain bike trails if necessary. We build on their progress so they'll want to come back and bike some more."

In some cases, tandem biking can lead to riding a two-wheeler independently. Debbie Zambo believes that cycling has been a great addition to the active life of her 16-year-old son, Keith, who has a developmental disability and is learning how to ride an adult BMX bike.

"I always felt it was important for Keith to go on family outings and participate in the activities," she reports. "He feels very proud of himself when he gets going on his bicycle, even if it is on the tandem bike. Physically, his balance is getting much better, and he is more outgoing and confident. The challenge has been for him to realize that he can do it on his own. I think it's been a really positive experience for him."

Hand cycling helps to promote independence in children with lower-body disabilities.

"Hand"ling the road

While tandem bikes require using the legs, hand cycles are pedaled with the arms. The bikes have three wheels and 21 gears to make navigating hills easier. As a rule, hand cycles are used on paved or gravel trails, not on mountainous terrain.

Beginners on a hand cycle will usually start out with an instructor keeping up beside them on in-line skates. This allows the instructor to assist the rider in action, helping him with problems that may arise as they get used to the bike. The participant, using her arm, shoulder, and back strength, can achieve real physical improvements, not to mention greater confidence on the bike. "For those with paraplegia, it's tough to get cardiovascular work in," said Peters. "But hand cycles really get them going. It's fun exercise, and the fact that it's outside just makes it better for them."

Most notably, hand cycling is great for promoting independence in kids with lower-body disabilities. "All kids love to ride bikes," said Matt Feeney, an avid biker who has paraplegia (level T-9). "People with a limitation or physical challenge might have felt left out before. Hand-cycling allows freedom from their wheelchairs, and they're not left out from participating with their friends on bikes. It's very liberating."

Tandem biking is a great way for individuals with visual impairments to enjoy the sport of biking.

Whether it is getting outside on the back of a tandem, or feeling the freedom of a hand cycle, bicycling is one of the best activities in promoting independence from a person's limitations. The ever-evolving technology is making it easier than ever for people with disabilities to participate with their able-bodied peers and friends. Feeney loves the feeling of being able to surpass his buddies on their bicycles. "The technology is really leveling the playing field for us," he said. "Now adaptive cycling programs can parallel

Hand cyclists use their arm, shoulder, and back muscles to propel the vehicle.

How to get started

First and foremost, all bikers should wear a helmet. When choosing a helmet, make sure the fit is snug and that the helmet covers the head, coming all the way down almost to the eyebrows.

Your local bike shop may have tandem bikes or hand-cycles for rent. Look for adaptive cycling equipment at your local Parks and Recreation Department, especially if they offer a special needs program. You can call your local children's hospital or rehabilitation center, or check your area for an adaptive sports program like the National Sports Center for the Disabled or a chapter of Disabled Sports USA.(See Resources for contact info).

able-bodied programs. It's very exciting." **EP**

Ryan Mayo is the public relations intern at the National Sports Center for the Disabled in Winter Park, CO. For more information, call the National Sports Center at: (970) 726-1540 or visit them on the Web at http://www.nscd.org.

Resources

The following organizations have more information on adaptive biking.

United States Cerebral Palsy
25 W. Independence Way
Kingston, RI 02881
(401) 874-7465
(401) 874-7468 (fax)
e-mail:uscpaa@mail.bbsnet.com
Web site: http://www.uscpaa.org

Amputee Coalition of America
900 E. Hill Ave., Ste. 285
Knoxville, TN 37915-2568
(888) AMP-KNOW (267-5669)
(423) 524-8772; (423) 525-7917
E-mail: ACAOne@aol.com
Web site:
http://www.amputee-coalition.org

National Ability Center
P.O. Box 682799
Park City, UT 84068-2799
(435) 649-3991
Web site:
http://www.nationalabilitycenter.org

Disabled Sports USA 451 Hungerford
Dr. Ste. 100
Rockville, MD 20850
(301) 217--0960 or 0963
(301) 217-0968 (fax)

Special Olympics International
1325 G. St, NW Ste 500
Washington, DC 20005
(202) 628-3630
http://www.specialolympics.com

Magazines dedicated to sports for people with disabilities

Palaestra Magazine
c/o Challenge Publications
P.O. Box 508
Macomb, IL 61455
Web site: http://www.palaestra.com

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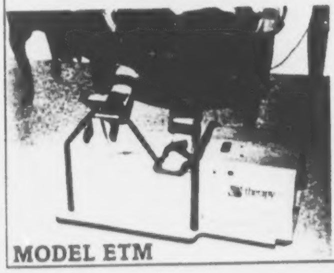
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Circle #62

11th World Congress of the International Association for the Scientific Study of Intellectual Disabilities (IASSID)

11th IASSID World Congress

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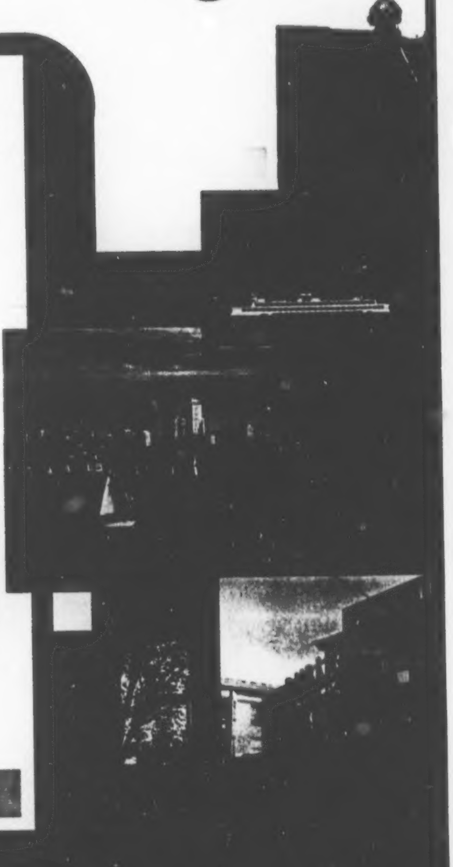

www.waisman.wisc.edu/iassid/index.html

IASSID

International Association for the Scientific Study of Intellectual Disabilities

1948
1998
WORLD HEALTH ORGANIZATION
ORGANISATION MONDIALE DE LA SANTE

For Congress information contact:
Convention Services Northwest
"IASSID Congress"
1809 7th Avenue
Seattle, Washington, USA 98101
Tel: 206-292-9198
Fax: 206-292-0559
email:tina@csnwseattle.com

Circle #16

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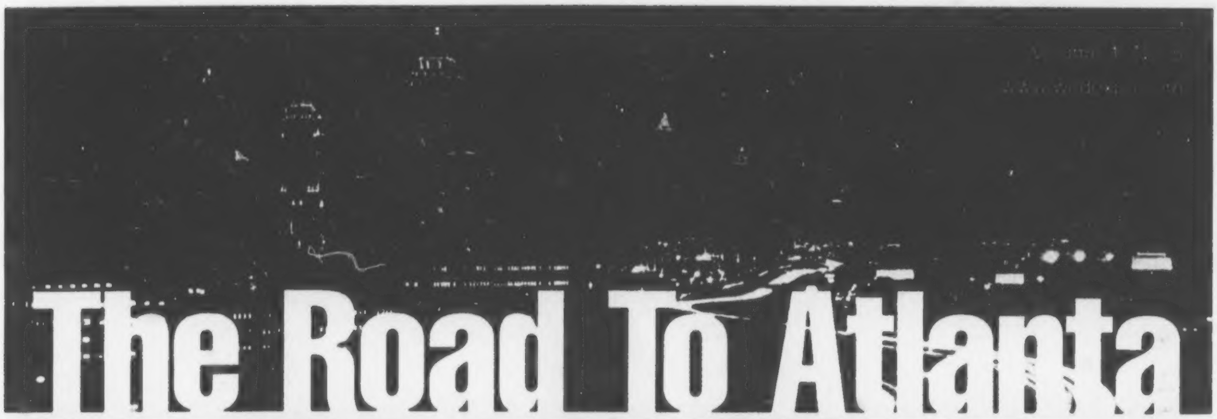

The Road To Atlanta

NOVEMBER 10-12 2000 WORLD CONGRESS & EXPOSITION ON DISABILITIES

WORLD CONGRESS & EXPOSITION ON DISABILITIES

WCD

Georgia International Convention Center Atlanta

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We understand that independence means different things to different people. For children with special needs, it could mean getting dressed by themselves, bathing themselves, or simply getting through the day dry. We also know that helping someone with special needs become more self-sufficient can be a major challenge, but can also be extremely rewarding.

When GoodNites® disposable absorbent underpants were introduced in 1994, they were intended for the seven million children in the U.S. who wet the bed at night. However, it quickly became evident that GoodNites® underpants also serve a very important role among individuals with special needs who experience delayed toilet training or bladder and/or bowel control difficulties.

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As we have worked to understand the needs and challenges faced by these children and their families, we have observed how parents and those who care for individuals with special needs have impacted research, therapies, funding, philosophies, and behavior. They have changed bus schedules, doorway dimensions, attitudes, policies, and the law. Most of all, they have moved people to action by their commitment to making a difference in the lives of the people they care for.

We have the highest respect for that dedication and commitment, and we share in the effort to make a positive difference in the lives of every family and child we serve. That's why we are proud to support the World Congress and Exposition on Disabilities. We hope that GoodNites® underpants will, in some way, help make life a little easier for individuals with special

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Dystonia Medical Research Foundation
Emory University
Epilepsy Foundation
Family Voices
Kennedy Krieger Institute
Marcus Institute
Muscular Dystrophy Family Foundation
National Down Syndrome Congress
National Family Caregivers Association
National Institutes of Health
National Multiple Sclerosis Society
National Parent Network on Disabilities
National Perinatal Association
Parent to Parent of Georgia
Shepherd Center
Special Olympics
TASH
The Arc of the United States
United Cerebral Palsy of Greater Atlanta
United Cerebral Palsy Foundation for Education & Research

WORLD CONGRESS & EXPOSITION ON DISABILITIES

WCD

November 10-12, 2000
Georgia International Convention Center
Atlanta, Georgia

PLUS: 250 exhibitors! As of March 2000, these include: AccessRD.com, Adaptive Children's Hospital, Columbia Medical Mfg., Daimler/Chrysler, DavisMade, Duraline Guldmann, Hard Manufacturing, Haverich Ortho-Sport, Hy-Gina Care, Keybowl, Pathways Awareness Foundation, PIE Medical, Plum Enterprises, PND Association Div./Abbott Labs, Sigma-Tau Pharmaceuticals, Sportime Abilitations, The Center for Fund, and Wheelchair Getaways. And the list is growing. Check next issue for more!

For Exhibitor and Attendee Info.: Call 877-923-3976 (877-WCD-EXPO)

Circle #88

n, technology and a whole lot of fun!

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40 education-packed conference sessions produced by the EP Foundation for Education, Inc.

EP Foundation
for Education, Inc.

For Families, Direct Support Professionals and People with Disabilities: Experienced parents and professionals share strategies and techniques for planning and problem-solving in the home, the family, the community and the world at large. Seminar and workshop topics will include: financial assessment and estate planning, health insurance issues, development of a lifetime medical plan, the medical home, caregiver burnout, and others.

For Physicians, Physical Therapists, Occupational Therapists, and Other Health Care Professionals: Symposia, lectures and workshops presented by international experts. CME credits through the Emory University School of Medicine; CEU credits through Emory and other approved accreditation providers. Topics to be covered include: newborn screening, neurology, epilepsy and seizure disorders, autism and PDD, ADD/ADHD, mental retardation and developmental disorders, mitochondrial disorders, inborn errors of metabolism, nutrition issues, and many more.

For Educators: For all those involved in the educational development of people with disabilities or special health care needs. CEU credits through the Council for Exceptional Children. Seminar subjects include: access, inclusion and mainstreaming, IDEA and Individual Education Plans (IEPs), assistive technology, learning disabilities, and more.

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mberly Clark, Lifestand, Maxi Aids/Hear-More, MetLife Financial Services, Mobility Designs, No Rinse Labs,
ediatric Neurotransmitter Disease), Poltron Corp., Pride Mobility Products, R. D. Equipment, Ross Products
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www.wcdexpo.com Ramps Up to the Superhighway

For detailed, up-to-date information on the first World Congress & Exposition on Disabilities (WCD), taking place November 10-12, 2000 at the Georgia International Convention Center in Atlanta, visit www.wcdexpo.com. The site provides information about this exciting, precedent-setting conference and trade show.

Visitors to this user-friendly site will easily be able to search and gather much needed information. An important aspect of WCD is it's educational forum. By clicking on **Conference** you will be able to access the 40 symposia and seminar topics to be presented by opinion leaders in their respective areas of expertise as well as the Advisory Board which created the program. The link to **Travel Info** allows you to find out about WCD's travel management firm, Expo Travel, Inc. and get information on special rates at nearby hotels and discounts on air travel.

The **Attendee Info** page links to a current list of WCD **exhibiting companies** which is expected to reach over 200 by the show's opening. This same page will soon be able to access a state-of-the-art, secure, **on-line registration** form. Registration for a show has never been so easy.

Exhibitors will learn how WCD markets to a **targeted audience** and allows exhibitors to **capture critical attendee information**. The **Floor Plan & Rates** page displays close-ups of the show floor. By exploring the WCD exhibit floor, visitors will view locations of the many value-added features planned for the show. These hands-on, educational and fun areas, such as the **Sports & Recreation and Assistive Technology Activity Centers** will soon be detailed on the site as well as an abundance of **sponsorship opportunities**.

Also coming in the near future will be information on the WCD **Career Fair**. This section of the show is planned to encompass three distinct areas: for people with disabilities, major national corporations and local businesses will look to meet directly with qualified job applicants; for health-care professionals, exhibitors will include hospitals, clinics, rehabilitation centers, etc.; and school districts and private schools will be on hand for special education professionals.

By visiting **www.wcdexpo.com** today, you will find out more about what makes this international conference and trade show so unique.

Check out our website! www.wcdexpo.com

Please send me information on the World Congress & Exposition on Disabilities, November 10- 12, 2000 at the Georgia International Convention Center in Atlanta

Name

Company

Address

City State Zip Code

Telephone Fax

Email

I am interested in:
☐ Exhibiting at the show
☐ Attending the show
☐ Enrolling in the Conference Program
☐ Attending the Career Fair

I am a:
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☐ Speech and Language Pathologist
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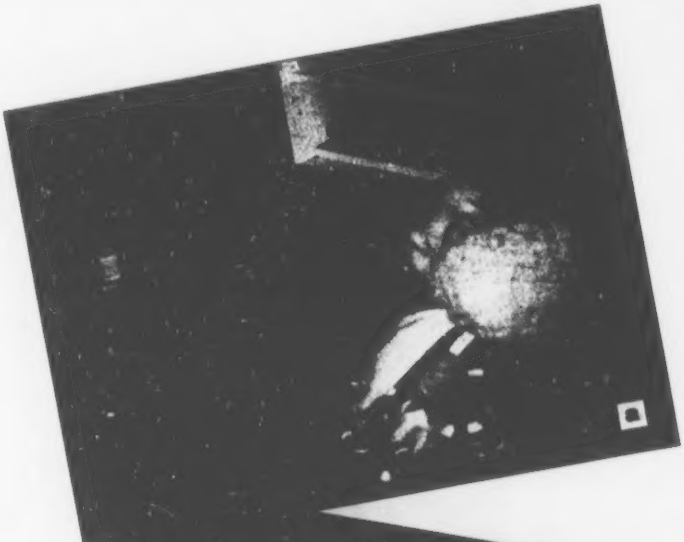
Circle #51

Switchin' in the Kitchen

by Jo Ann Hughes and Debby Entwistle



More than any other room in the house, the kitchen has got to be the most stimulating to the senses. Think of all the sights, sounds, smells, and tastes! Food preparation also provides endless opportunities for tactile experiences and for motor and cognitive skill development. Take a few pieces of adaptive equipment, several kitchen gadgets, and a little ingenuity and you have the ingredients for success for all.

Photos

a. Deja' uses a pour switch to transfer chopped green peppers into the vegetable soup pot.

b. Mitchell and a volunteer prepare to blend homemade salad dressing.

c. Oh, the joys of whipped cream! Whitney uses a mixer attached to a control box which is activated by a single switch.

Recipes to Try Switchin' in Your Kitchen

Fruit Salad
Ingredients:
Fruit
1. Use switch-activated a) electric peeler b) electric knife to peel and slice fruit.
2. Use switch-activated blender to puree.

High Protein Edible Play Dough
Ingredients:
1 cup of peanut butter
1 cup corn syrup
1 1/4 cup powdered sugar
1 1/4 cup powdered milk
Mix together to a good consistency for molding.

Augmentative and Adaptive ideas:
1. Mix dough in food processor or mixer with control box and switch.
2. Use pour switch to add dry ingredients.

Extra suggestions:
1. Use candy molds and cookie cutters to shape dough.
2. Press chocolate chips, raisins, M & Ms, etc, into your creations for added color, textures, detail, and taste.

Fruit Smoothie
Fruit smoothies can be made many different ways. Some are all fruit, others have yogurt or milk in them. All are mixed in a blender and can be "frozen" by adding crushed ice.

Pineapple-Strawberry-Mango
1 cup strawberries
2 cups pineapple juice
1 cup diced mango

Orange Banana
3 cups orange juice
2 cups canned apricots
2 bananas

Yogurt Smoothie
1 cup yogurt (lemon or vanilla)
1 cup orange juice
1 cup pineapple juice
2 cups peaches

You can use fresh, frozen, or canned fruit. Be creative!

Augmentative and Adaptive Ideas:
1. Use electric peeler, knife, and blender with control box and switch.
2. Use ice crusher with control box with switch (to add another step and more noise). Ice cubes work just as well.
3. Garnish with fresh fruits cut in chunks and place on skewers with cherries.

d. Matthew helps a volunteer cut peaches for peach jam with an electric knife (using a grip switch).

Kitchen Gadgets

- Electric peelers, knives, blenders, mixers, food processors, and salad shooters are must haves for the adapted kitchen. Scout out your local discount store's kitchen department and experiment. In many instances, your child will not handle the device directly, so safety concerns may not be the same.
- We found a battery-operated sifter in The Pampered Chef® catalog. It is a great addition to our pantry.

Some of our most successful projects

- The best times are had in the kitchen if the recipe has many steps and several different appliances or gadgets can be used. If you are pressed for time, however, even the opportunity for your child to do one quick step of a simple task is lots of fun. How about grinding coffee in the morning?
- Projects that offer the opportunity to explore tastes and textures of different foods have been entertaining for everyone. Fruit smoothies are a great way to experiment with new and unusual fruits. This project offers immediate gratification! (See "Recipes" box.)

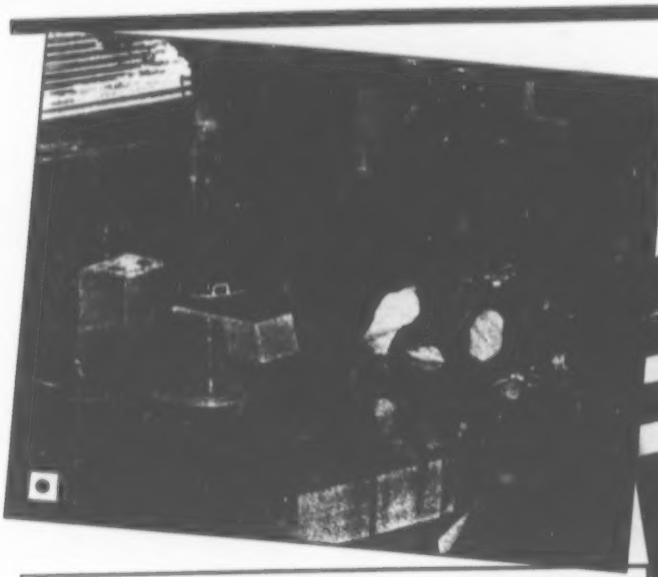
ADAPTIVE DEVICES

- A variety of switches are available to enable access to electric and battery-operated appliances. AbleNet®, Inc. and Enabling Devices®-Toys for Special Children are two sources we use frequently.
- The Power Link control unit from AbleNet, Inc. converts electric appliances to allow switch activation.
- Voice out-put augmentative communication devices provide lots of kitchen chatter and some devices also work as a switch. We use Ablenet, Inc.'s "Big Mac", "One Step", and "Step by Step" devices, as well as "Cheap Talk" available through Enabling Devices.

continued on page 66

continued from page 65

- Battery interrupters, available through both companies, make adapting battery powered gadgets a snap. (See "Resources" Box.)



Photos

e. Summer means peaches, and peaches mean jam. Tan chops them up as fast as he can!

f. Larry (r.) and Sue prepare garden grown herbs for herbed vinegars.

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Circle #86

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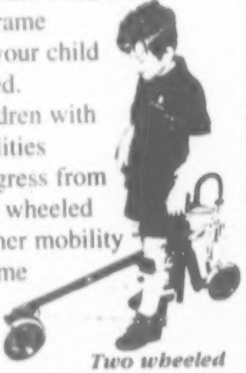

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www.hartwalker.com

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Circle #43

g. Nathan (l.) and Kristen (seated) are helping JoAnn (r.) and two volunteers follow the directions for making delicious pickles.

Additional Ideas

- Besides the adaptor devices that can be purchased, we have found a wonderful resource in our local gas and electric company for having battery-operated devices adapted. Electricians have volunteered their time to do this for us and although you can learn to do it yourself, you need a soldering iron and some knowledge of circuitry.
- Remember to add music to your recipe for fun. We almost always have someone in charge of operating the tape player with his or her switch during kitchen activities.
- Homemade food items make great gifts and salable items for fundraisers. Our bazaar would be sorry indeed if it were not for the jams, jellies, pickles, and baked goods we have for sale each year.

HAPPY SWITCHIN'! **EP**

Debby Entwistle is a special education teacher and Jo Ann Hughes is an occupational therapist at the Pediatric Convalescent Center, The Home of the Innocents, Louisville, KY.

Resources

Ablenet®, Inc. • (800) 322-0956
http://www.ablenetinc.com

Enabling Devices®-Toys for Special Children
(800) 832-8697 • http://www.enablingdevices.com

The Pampered Chef® Catalog
(800) 266-5562 (USA only) • (800) 342-2433 (Canada)
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Circle #61

Developmental Disabilities Councils

In our 2000 Resource Guide, we printed a listing of Developmental Disabilities Councils. We made every attempt to make this listing accurate, but encountered difficulties in the verification process, which resulted in some of the listings being incorrect. Listed below are the Developmental Disabilities Councils for each state, which have been confirmed. Special thanks to Lucy Walker, Public Information Specialist at the Texas Council for Developmental Disabilities for her help in this.

NADDC—NATIONAL ASSOCIATION OF DEVELOPMENTAL DISABILITIES COUNCILS
1234 Massachusetts Ave., NW, Ste. 103
Washington, DC 20005
Phone: (202) 347-1234
Fax: (202) 347-4023
✉rprice@naddc.org
Web site: http://www.naddc.org

CONSORTIUM OF DEVELOPMENTAL DISABILITIES COUNCILS
2102 Weatherton Dr.
Wilmington, DE 19810
Phone: (302) 529-7270
Fax: (302) 529-7271
✉info@cddc.com
Web site: http://www.cddc.com

THE ALABAMA DEVELOPMENTAL DISABILITIES COUNCIL
RSA Union Building
100 North Union St.
P.O. Box 301410
Montgomery, AL 36130-1410
Phone: (334) 242-3973
Fax: (334) 242-0797

THE ALASKA DEVELOPMENTAL DISABILITIES COUNCIL
P.O. Box 240249
Anchorage, AK 99524
Phone: (907) 269-8990
Fax: (907) 269-8995
✉dmaltman@health.state.ak.us

THE ARIZONA DEVELOPMENTAL DISABILITIES COUNCIL
1717 W. Jefferson
Site Code 074Z
Phoenix, AZ 85007
Phone: (602) 542-4049
Fax: (602) 542-5320

THE ARKANSAS DEVELOPMENTAL DISABILITIES COUNCIL
Freeway Medical Tower
5800 West 10th St., Ste. 805
Little Rock, AR 72204
Phone: (501) 661-2589
Fax: (501) 661-2399
✉scrolley@mail.doh.state.ar.us

THE CALIFORNIA DEVELOPMENTAL DISABILITIES COUNCIL
2000 "O" St., Ste. 100
Sacramento, CA 95814
Phone: (916) 322-8481
TDD: (916) 324-8420
Fax: (916) 443-4957
Web site: http://www.scdb.ca.gov

COLORADO DEVELOPMENTAL DISABILITIES COUNCIL
777 Grant St., Ste. 304
Denver, CO 80203
Phone (V/TDD): (303) 894-2345
Fax: (303) 894-2880
✉CDDPC@aol.com

COMMONWEALTH OF THE NORTHERN MARIANA ISLANDS
CNMI Governor's DD Council
Capitol Hill, Bldg. #1312
Post Office Box 2565
Saipan, MP 96950
Phone (V/TDD): 011-670-664-7000
Fax: 011-670-664-7030
✉dd.council@saipan.com
Web site: http://www.cnmiddcouncil.org

CONNECTICUT COUNCIL ON DEVELOPMENTAL DISABILITIES
460 Capitol Ave.
Hartford, CT 06106-1308
Phone: (860) 418-6160
TDD: (860) 418-6172
Fax: (860) 418-6003
✉ed.preneta@po.state.ct.us
Web site: http://www.state.ct.us/ctcdd

THE DELAWARE DEVELOPMENTAL DISABILITIES COUNCIL
Margaret M. O'Neil Bldg.
410 Federal St., Ste. 2
Dover, DE 19901
Phone: (302) 739-3333
TDD/Help Line: (800) 464-HELP (In-State)
(800) 273-9500 (Out-of-State)
Fax: (302) 739-2015
✉jlinehan @state.de.us

DISTRICT OF COLUMBIA DEVELOPMENTAL DISABILITIES COUNCIL
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801 East, Rm. 1301
Washington, DC 20032
Phone: (202) 279-6085
Fax: (202) 279-6090

FEDERATED STATES OF MICRONESIA
Department of Education
Palikir, Pohnpei, FM 96941
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FLORIDA DEVELOPMENTAL DISABILITIES COUNCIL
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GEORGIA GOVERNOR'S COUNCIL ON DEVELOPMENTAL DISABILITIES
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Atlanta, GA 30303
Phone: (404) 657-2126
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Fax: (404) 657-2132
Toll Free: 1-888-ASK-GCDD
(1-888-275-4233)
✉GCDD@aol.com
Web site: http://www.ga-ddcouncil.org

THE GUAM DEVELOPMENTAL DISABILITIES COUNCIL
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Tiyan, Guam 96913
Phone: (671) 475-9127
TTY: (671) 475-9128
Fax: (671) 475-9128
✉lada@netpci.com

THE HAWAII DEVELOPMENTAL DISABILITIES COUNCIL
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Honolulu, HI 96814
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Fax: (808) 586-7543
✉hiddc@pixi.com

THE IDAHO DEVELOPMENTAL DISABILITIES COUNCIL
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Boise, ID 83720
Phone: (208) 334-2178 or
(800) 544-2433
TTY: (208) 334-2179
Fax: (208) 334-3417
✉msword@icdd.state.id.us
Web site: http://www.state.id.us/icdd/

THE ILLINOIS DEVELOPMENTAL DISABILITIES COUNCIL
830 S. Spring St.
Springfield, IL 62704
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✉lsherell@pop.state.il.us
Web site:
http://www.state.il.us/agency/ipcdd

INDIANA GOVERNOR'S COUNCIL FOR PEOPLE WITH DISABILITIES
143 W. Market St., Harrison Bldg., Ste. 404
Indianapolis, IN 46204
Phone: (317) 232-7770
Fax: (317) 233-3712
✉gpcpd@in.net

THE IOWA DEVELOPMENTAL DISABILITIES COUNCIL
617 E. Second St.
Des Moines, IA 50309
Phone: (515) 281-9083
Fax: (515) 281-9087
✉bharker@dhs.state.ia.us

THE KANSAS DEVELOPMENTAL DISABILITIES COUNCIL
Docking State Office Bldg.
915 S.W. Harrison, Rm. 141
Topeka, KS 66612-1570
Phone: (785) 296-2608
Fax: (785) 296-2861
✉jrhys@idir.net

THE KENTUCKY DEVELOPMENTAL DISABILITIES COUNCIL
100 Fair Oaks Lane/Stop#4EF
Frankfort, KY 40621-0001
Phone: (502) 564-7841 or
(800) 928-6583
Fax: (502) 564-9826
✉Pat.Seybold@mail.state.ky.us

THE LOUISIANA DEVELOPMENTAL DISABILITIES COUNCIL
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Baton Rouge, LA 70821-3455
Phone: (225) 342-6804
Fax: (225) 342-1970

THE MAINE DEVELOPMENTAL DISABILITIES COUNCIL
139 State House Station
Augusta, ME 04333-0139
Phone: (207) 287-4213
Fax: (207) 287-8001
✉peter.stowell@mmp.org

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Box 10
Baltimore, MD 21201
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Fax: (410) 333-3686
✉mg44@umail.umd.edu

THE MASSACHUSETTS DEVELOPMENTAL DISABILITIES COUNCIL
174 Portland St., 5th Floor
Boston, MA 02114
Phone: (617) 727-6374
TTY: (617) 727-1885
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✉dshannon@mddc.state.ma.us

MICHIGAN DEVELOPMENTAL DISABILITIES COUNCIL
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Lansing, MI 48913
Phone: (517) 334-6123
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Fax: (517) 334-7353
✉collinsve@state.mi.us

MINNESOTA GOVERNOR'S COUNCIL ON DEVELOPMENTAL DISABILITIES
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658 Cedar St.
St. Paul, MN 55155
Phone: (651) 296-4018
TDD: (651) 296-9962
Fax: (651) 296-7200
✉admin.dd@state.mn.us
Web site: http://www.mncdd.org
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Fax: (601) 359-6295

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✉kconklin@mail.state.mo.us

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Helena, MT 59624
Phone: (406) 444-1334
Fax: (406) 444-5999

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Department of Health and Human Services
301 Centennial Mall South, Box 95044
Lincoln, NE 68509-5044
Phone: (402) 471-2330
TDD: (402) 471-9570
Fax: (402) 471-0183
✉doh7111@vmhost.cdp.state.ne.us

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TTY: (775) 687-3388
Fax: (775) 687-3292

THE NEW HAMPSHIRE DEVELOPMENTAL DISABILITIES COUNCIL
The Concord Center
Unit 315, 10 Ferry St.
Concord, NH 03301-5004
Phone: (603) 271-3236
TDD/Voice Relay: (800) 735-2964
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✉nhddcncl@aol.com

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P.O. Box 700
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✉njddc@njddc.org

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TDD: (614) 644-5530
Fax: (614) 466-0298
✉mr_ddc_zwyer@ohio.gov

OKLAHOMA PLANNING COUNCIL FOR DEVELOPMENTAL DISABILITIES
3033 N. Walnut, Ste. 105E
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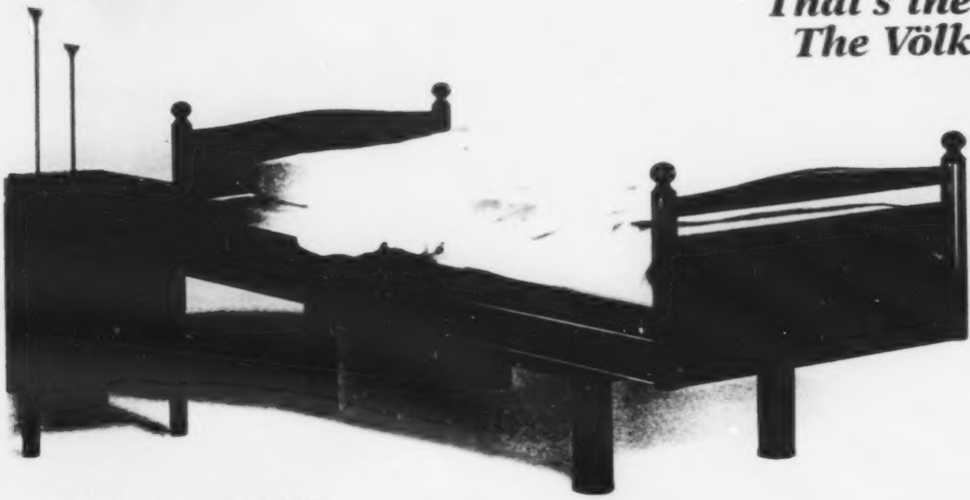

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🖂RIDDC@RIDDC.org
Web site: http://www.RIDDC.org

THE SOUTH CAROLINA DEVELOPMENTAL DISABILITIES COUNCIL
1205 Pendleton St., Rm. 372
Columbia, SC 29201
Phone: (803) 734-0465
TDD: (803) 734-1147
Fax: (803) 734-0241
🖂clang@govoepp.state.sc.us

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Fax: (605) 773-5483
🖂arlene.poncelet@state.sd.us
Web site: http://www.state.sd.us/dhs/ddc

THE TENNESSEE DEVELOPMENTAL DISABILITIES COUNCIL
5th Floor, Cordell Hull Bldg.
425 Fifth Ave., North
Nashville, TN 37243-0675
Phone: (615) 532-6615
TTY: (615) 741-4562
Fax: (615) 532-6964
🖂tnddc@mail.state.tn.us

TEXAS COUNCIL FOR DEVELOPMENTAL DISABILITIES
4900 N. Lamar Blvd.
Austin, TX 78751-2399
Phone: (512) 424-4080
TDD: (512) 424-4099
Fax: (512) 424-4097
🖂TXDDC@rehab.state.tx.us
Web site:
www.rehab.state.tx.us/tpcdd/Index.htm

THE UTAH DEVELOPMENTAL DISABILITIES COUNCIL
555 E. 300 South, #201
Salt Lake City, UT 84102
Phone: (801) 533-4128
Fax: (801) 533-5305
🖂 cchamble@state.ut.us

THE VERMONT DEVELOPMENTAL DISABILITIES COUNCIL
103 S. Main St.
Waterbury, VT 05671-0206
Phone: (802) 241-2612
Fax: (802) 241-2979
🖂vtddc@wpgate1.ahs.state.vt.us

THE VIRGINIA DEVELOPMENTAL DISABILITIES COUNCIL
Ninth St. Office Bldg.
202 N. 9th St., 9th Floor
Richmond, VA 23219
Phone: (804) 786-0016
TDD/Voice: (800) 846-4464
Fax: (804) 786-1118
🖂parsonbs@vbpd.state.va.us

VIRGIN ISLANDS DEVELOPMENTAL DISABILITIES COUNCIL
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Kingshill, St. Croix, Virgin Islands 00851
Phone: (809) 778-9682
Fax: (809) 778-9250

THE WASHINGTON DEVELOPMENTAL DISABILITIES COUNCIL
P.O. Box 48314
906 Columbia St., SW
Olympia, WA 98504-8314
Phone: (360) 753-3908 or
(800) 634-4473
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🖂edh@cted.wa.gov
Web site: http://www.wa.gov/ddc

THE WEST VIRGINIA DD COUNCIL
110 Stockton St.
Charleston, WV 25312-2521
Phone: (304) 558-0416
TDD: (304) 558-2376
Fax: (304) 558-0941
🖂wisems@wvnvm.wvnet.edu
Web site: http://www.state.wv.us/ddpc

THE WESTERN CAROLINA ISLANDS TRUST TERRITORIES OF THE PACIFIC
Trust Territories Health Council/
MacDonald Memorial Hospital
KOROR, Palau, WCI 96940
Dr. Minoru Ueki, MD

THE WISCONSIN DEVELOPMENTAL DISABILITIES COUNCIL
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P.O. Box 7851
Madison, WI 53707-7851
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Fax: (608) 266-3906
🖂wiswcdd@dhfs.state.wi.us

THE WYOMING DEVELOPMENTAL DISABILITIES COUNCIL
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Circle #20

Assistive Technology 101

Assistive technology professional, R.J. Cooper, explains the jargon and shares some practical advice on putting together the right computer system to handle adaptive equipment and special software programs.

Choosing a computer system to meet a user's special needs

by R.J. Cooper

Assistive technology (AT) and how it can help their child who has special needs is often a mystery to many parents. Adding to the lack of general knowledge about AT is the fact that AT items are not readily available—they cannot be purchased at regular computer stores. In addition, literature, products, and knowledge about AT exist only within the AT community of researchers, developers, retailers, and teachers. It is time for us bring AT to a larger audience, and in effect, "blow its cover."

What Is AT?

AT is any device or adaptation that helps a person function in his or her daily life. The IDEA '97, (Individuals with Disabilities Education Act) defines AT as "any item, piece of equipment, or product system ... that is used to increase, maintain, or improve functional capabilities of a child with a disability."

For the purposes of this article, we will be looking at AT as it relates to computers and what a parent needs to get started. Let's begin by taking a look at your basic computer.

Computer systems

"What kind of computer should I get?" is a question people often ask me. Several years ago, brand, size, and specifications (or "specs") mattered. In fact, experts advised exploring the programs, or software, that you wanted to run on your computer, and then purchasing the computer that would support the software. Today, those issues are no longer critical. All name brand computers are, in my experience, very good. Personally, I lean toward Macintosh®, because they are easy to set up, expand, maintain, and use. PC compatibles (PCs) are almost always more complex in all areas.

PCs use an operating system (OS) called Windows®. An OS is the software that allows you to interact with your computer. Currently, the versions of Windows OS include 95, 98, or (soon to be) 2000, and Windows 3.1. Though it is more technical than this, simply put, Windows 3.1 is built upon DOS, which is also an operating system. On a Mac, it is called the Mac OS (up to nine versions as of now).

The world has "chosen" Windows—meaning that most software programs are designed for a Windows system. Most AT software is available for both Mac and Windows. However, there are a significant number of titles that are for either Mac *or* Windows. If you have a specific program in mind, check with its producer to make sure you are purchasing the right type of computer.

If operating Windows will be a necessity in the near future for your child, then perhaps it is best to start now. But if you do go the Windows route, try to line up a support person, such as a friend, teacher, or even a sales person from your local computer store, who is computer savvy and willing to share his or her knowledge with you.

When you buy your computer, do not worry about specifications such as RAM (or memory), hard drive space, speed, etc. Today, these specs are all great: you can no longer buy an underpowered computer. All of today's computers have plenty of hard drive space—where you store things that will stay on your computer after you turn your computer off. Two gigabytes or "gigs" is standard; (the G3 by Macintosh that I just purchased has 9 gigs). They all have sufficient memory with 16 MB (megabytes) being a minimum, and 32 MB becoming the standard (my G3 has 128 MB).

I recommend you stick with name brands (Apple, IBM, Compaq, HP, Packard Bell, etc.). Warranty should be a consideration, as should toll-free tech support. Apple, IBM, Gateway, and Dell always score high in these areas. I strongly suggest you not purchase a 'home-grown' computer put together by a friend or a small computer store. Computers such as these usually use

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lesser quality or less compatible parts from many manufacturers, often with no support after the sale. Prices on great computers are so low these days, that there is no excuse for not getting a computer with a name brand.

Recommendations

I have three recommendations for whichever computer system you choose:

1) Get a 17" monitor. The difference between a 13" and 15" monitor is small; however, the difference between a 15" and a 17" is quite significant. A 17" monitor has a "viewable" area of 15-16". I consider 17" a minimum for children with special needs. The cost of a regular 17" monitor is about $300. Try ViewSonic, which are sold everywhere.

LCD (liquid crystal display) monitors have a viewable area equal to their size: in other words LCDs that are 15" have a viewable area of 15" and run about $1,000. LCDs are also known as "flat panel displays" because they are thin. Only 1" thick, lightweight, and with bright, clear picture quality, LCDs are wonderful. Also, they can be mounted, using special LCD arms, in positions that regular monitors cannot. Unfortunately, 17" LCD monitors are expensive (about $3,000). Once again, with either a regular or LCD monitor, go name brand.

Besides size, dot pitch is another specification for monitors. Dot pitch is a measure of a monitor's clarity; the smaller the dot pitch, the clearer your picture will be. It is more technical than that, but the effect is overall clarity. A standard dot pitch is .28, but you can go all the way up to .40 if the only things that will be on the monitor are large objects. It is only when you are using small, fine-lined items, like small font text, that dot pitch becomes significant.

Be aware that any computer monitor, whether it is for a Mac or a PC, will work with a Mac, whereas a Mac monitor will not work with a PC. Sometimes, Mac-specific monitors are priced a bit higher than the more mass-marketed monitors for PCs. With the addition of a special Mac video adapter, like that from MacAdapt, any monitor will work with almost any Mac. The LCD monitor will require the adapter listed above, or may come with one.

2) Get good, big speakers. Most systems come with small speakers. I have found that, for my work with children with special needs, especially those functioning at the cognitive level of a 0- to 2-year-old, I need sound to be clear and bold. Many companies make great speakers these days. I prefer the Altec and PC SoundWorks lines (both sold just about everywhere). Some are two- piece systems and others are three pieces with a large sub-woofer (by large I mean 6"x6"x9", which is large for a computer speaker). The three-piece systems sound superior, and have better bass response.

3) Get a floppy drive. Although all computers have CD-ROM drives these days, and floppy drives are certainly on the way out, they are still valuable. There are external ones available for both G3s and iMacs for under $100 Or you can get the Imation SuperDisk USB for about $150, which will be able to read or store information on regular 1.44 MB floppies and the Imation 120MB disks, which run about $10 each. You can get a floppy drive at any Mac or PC retail store or online mail-order stores like Macwarehouse, Maczone, PCzone or PC Warehouse. As for the CD-ROM drives, do not be concerned with their speed. They are all at least 12 times faster than what was available five years ago.

Customizing for special needs

You now have the computer and it is time to adapt or customize it for special needs. First, you can analyze your child's needs: break down the need to "access" or "instructional," with some overlap for each. By "access" I mean that some computer adaptation may be necessary for your child with special needs to use it, but your child may not have need of special instructional software. Your

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Circle #41

• •

child might be able to use off-the-shelf, conventional software once he or she is able to operate the computer.

"Instructional" means that you still might have some access issues, but you will also need specialized software that is designed to teach a child at his or her cognitive level.

Instructional software usually teaches, drills, or tests something, such as number concepts, or picture matching. You can buy instructional software at computer stores, but this software is usually geared toward people who function at a cognitive level of 2 years and above.

"Special" instructional software usually displays its content more slowly than regular software, the graphics are more defined, everything might be spoken as well as in print, and the choices are usually fewer, so the user does not "get lost." Regular software rarely has these special needs options. Next month, we will look at specific access adaptations for computers, and where to find them. **EP**

R.J. Cooper holds a BA in developmental psychology and has been working with, and developing technology materials for people with special needs for over 16 years. He is the founder and president of R.J. Cooper and Associates, which develops and sells its own AT hardware and software programs. RJ can be reached via e-mail at: http://www.rjcooper.com.

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Circle #48

Part 3

Can We Talk?

PARENTS' PERSPECTIVES ON AAC:

Selecting the right system, now and as your child grows

by Peggi McNairn, PhD, CCC/SLP, ATP, and Cindy Shioleno, MEd

For some families, the birth of a child with a disability can be overwhelming, throwing them into an unknown world of technical and medical jargon. This was the case for Frank and Laura Warburg of Louisville, Kentucky. Nine years ago, their daughter, Candice, was born with cerebral palsy, leaving her unable to walk or talk like other children her age.

"We needed someone to help us to see the possibilities," says Laura Warburg. "When it came to communication, she (Candice) could not verbalize sounds consistently or isolate her pointer finger to indicate a choice. We knew what made her cry, though. And we knew what made her laugh out loud. We could see which direction she was looking when it came to some early choice making. That was enough for us in those early days."

AAC AS AN ONGOING PROCESS

As important as selecting the most appropriate communication system is for the child, it is even more important to realize that this selection is not just a one-time event, but an ongoing life-long process. As the communication needs of the child change, so will the need for different technology. Dr. Hal and Christi Urschel of Dallas, Texas have found this to be particularly true for their son, Chance, 4, who was diagnosed with holoprocencephaly (a neurodevelopmental disorder with multiple causes, including genetic defects). Chance faces significant motor challenges each day. "We have had to train Chance's caregivers several times in different light and high tech options," says Dr. Urschel. "As his language skills continue to improve, they have had to learn new strategies and new technology because what was once an appropriate option became suboptimal."

"We all grow out of stuff," reflects Brenda Klauditz, of Toms River, New Jersey, the mother of 17-year-old Daniel, who was born with cerebral palsy. "There is not a piece of technology that will last forever. It is always a good idea to have some insight into what is out there for our children." As Laura Warburg has discovered with Candice, "What did not work yesterday, many times will work tomorrow."

ADVOCATING FOR OUR CHILDREN

Although AAC devices may be unfamiliar to families, it is important that parents learn as much as possible so that they will be able to advocate for whatever is best for their children. "As a parent," says Brenda Klauditz, "I seem to have to advocate for anything that my son needs. We have had to battle daily with the school and have been in and out of court for the past six years."

According to Brenda, "My recommendations to parents are to know your children, believe in them, challenge them, have goals for them, expose them and stimulate them. Get involved, because ultimately it will be your job."

In 1977, to help parents advocate for the needs of their children, the United States Congress provided funding to each state to establish non-profit advocacy organizations. These organizations are charged with protecting and advocating for the legal rights of people with disabilities. For assistance, parents can contact the National Association of Public Advocacy Services at (202) 408-9514.

BECOMING AN INFORMED CONSUMER

Once the AAC assessment process has been completed and the needs of the child have been determined, the search for the device that will most closely match the needs of the child begins. During the evaluation process, the child and family should have the opportunity to become familiar with several devices to find the "best fit." During these trial periods, several important questions should be answered. (See Questions, page 76.)

IS THERE A RENTAL PROGRAM?

After previewing the equipment, the child needs a period of time to experiment with and explore the device. Parents should ask AAC vendors what type of rental program their company offers. It is also important to ask if the money used for the rental device can be applied to the purchase of the device. Many companies offer a brief loaner program at no cost to the consumer. It is important for the child to have the opportunity to use the device outside the evaluation or therapy center. How the device

[redacted]

Parents of children who use augmentative and alternative communication (AAC) devices share helpful information, stories, and insights about their experiences with the process of selecting and using communication systems.

functions at home, school, and the community is important.

DOES YOUR DEVICE HAVE A WARRANTY?

Because most high tech AAC devices may cost $5,000 or more, an important question families should ask is, "What type of warranty or service contract does your company provide?" Not only do consumers need to know if a warranty is provided, they also need to know what this warranty covers and for what period of time. Some manufacturers provide 6-12 month warranties that cover damages incurred from "normal wear and tear." Some may provide a warranty on software, but not hardware. It is important that all terms, conditions, and restrictions be clearly defined and explained in writing.

The family needs to have a contingency plan in place in the event that repairs take several months. "Is there a loaner device available to our child during the repair period?" is a question that should be answered before the service is required.

"Does your company provide an extended warranty period?" is another question that families should ask. High tech devices are designed to last several years. However, repairs to older devices can be extremely costly. Extended warranties or service contracts can save a family thousands of dollars.

WHAT KIND OF CONSUMER SUPPORT DOES YOUR COMPANY PROVIDE?

An important service that many AAC manufacturers are now providing to families and consumers is information and support in the area of funding. Working with a company that has a knowledgeable funding specialist can often help families discover funding sources unique to their state or town. Asking for information on funding sources and regulations may be the first step in obtaining an AAC device.

Many families and professionals will also require specialized, hands-on training in the use of high tech AAC devices. It is important to know what type of training the manufacturer is willing to provide and what this training will cost. Recalls Brenda Klauditz, "I am lucky that I do well with manuals, as I have never had any of the help I often hear others talk of. I find that people do not have experience in what Daniel is doing and needing. I have learned to specialize in my son's needs."

In addition to training, many AAC manufacturers offer some type of

continued on page 76

Augmentative and Alternative Communication

According to the American Speech-Language-Hearing Association in Rockville, Maryland, AAC "refers to all communication that supplements or augments speech." AAC covers a broad range of techniques, strategies, and devices, from simple picture boards to sophisticated, computer-based communication devices with synthetic voices. Other examples may include facial expressions, gestures, body postures, sign language, drawing, and writing.

Light Tech AAC Devices
Simple AAC devices that do not use electronic or computer parts, such as the use of pictures attached to a board or inexpensive devices that can record a voice, are often referred to as "light" or "low" tech devices. These simple devices are typically used to facilitate the development of emerging language and communication skills, such as choice making. However, even light tech AAC options can sometimes prove overwhelming, time-consuming, and cumbersome.

High Tech AAC Devices
Often, because light-tech systems are so simple, they may also prove to be very limiting. When this occurs, high tech AAC systems should be introduced. Today, there are many high tech communication devices on the market. Some devices are manufactured specifically for communication and are referred to as "dedicated" communication devices. Other devices, called "integrated" communication devices, are built upon a standard computer platform. Special communication software is typically added to enhance the computer's ability to function as a communication device.

Light Tech vs. High Tech
The use of light tech devices does not exclude the additional use of high tech AAC devices. In fact, AAC is most effective when thought of as a "system" rather than a specific device or piece of equipment. The greater the variety of communication options that a child has to choose from, the better opportunity he/she will have in communicating his/her thoughts in every situation.

Using this system approach avoids the pitfalls of relying on only one device or technique. High tech systems may break down and need repairs, with light tech systems serving in the interim. Also, some situations, such as bathtime, may not lend themselves to the use of a high tech system.

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Circle #23

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technical assistance over the telephone or the internet. "I used technical support over the phone quite a bit in the beginning. They were really great," says Brenda.

Nothing is more frustrating than buying a new computer only to discover that it is outdated the next week. The same concern exists for AAC devices. When considering the purchase of any AAC device, the family should inquire what options are available for upgrading their child's device. Some companies offer free lifetime upgrades of their software while others charge a substantial fee.

WHAT DOES THE INITIAL PRICE QUOTE INCLUDE?

To avoid misunderstandings or unpleasant surprises, it is important for the consumer to obtain an itemized price quote for the AAC equipment. Many companies will often list only the price of the hardware, omitting the additional cost of the communication software, warranties and/or training.

IS THERE A FAMILY IN THE AREA WHO USES YOUR EQUIPMENT THAT I CAN TALK TO?

Meeting and talking with a family who has been through the selection process is an invaluable experience for most families. As Laura Warburg recalls, "We would have gained so much in those early days (and today) from one-on-one mentoring by a family with a child with similar abilities."

continued on page 78

Questions to Ask AAC Manufacturers

Is there a rental program?
- **Can the rental be applied towards the purchase?**
- **Do you have a free loaner program before the purchase?**

Does your device have a warranty?
- **What type of warranty does your company provide?**
- **Do you provide a loaner device during the repair period?**
- **Does your company provide an extended warranty?**

What kind of consumer support does your company provide?
- **Do you have a funding specialist on staff?**
- **Do you provide training?**
- **How much does the training cost?**
- **Do you provide technical assistance?**
- **What type of technical assistance do you provide?**
- **What options do you provide for upgrading the device?**

What does the initial price quote include?
- **Does this price quote include everything my child will need for communication?**

Is there a family in the area who uses your equipment that I can contact?

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Breaking through the barriers

Circle #34

About the parents:

Ed and Brenda Klauditz live in Toms River, NJ, with their 11-year-old son, Andrew, and 17-year-old son, Daniel.

Dr. Hal and Christi Urschel live in Dallas, Texas, with their 4-year-old son, Chance.

Frank and Laura Warburg live in Louisville, KY, with their 9-year-old daughter, Candice, and 6-year-old son, Joey.

continued from page 76

IS YOUR COMPANY COMMITTED TO INNOVATION?

Finding a company that provides innovations that meet different and changing needs through a variety of solutions is an important consideration in the partnership between consumer and manufacturer.

"During our initial search for the most appropriate AAC device for Chance, we discovered that many companies felt that they did not need to improve the hardware component of their devices," says Dr. Urschel. "Instead they focused most of their time on software improvements. Consequently, their devices continue to be big, bulky, and much slower than the fastest laptop computer."

For families, the selection and implementation of the most appropriate AAC device for their children is no small feat. In spite of this complicated decision-making process, the Urschel, Warburg, and Klauditz families all agree that the rewards of being able to communicate with their children are well worth the effort.

Peggi McNairn, PhD, CCC/SLP, ATP, is in private practice and serves as Texas Woman's University's Distance Learning Coordinator at the Education Service Center in Ft. Worth, Texas. She can be contacted at Quick Tech I.D.E.A.S.S., 215 Spanish Moss, Arlington, TX 76018-1540; telephone: (817)450-9561; E-mail: pmcnairn@aol.com.

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The authors welcome questions and comments.

RESOURCES

An excellent resource of information for parents on the many devices currently available is the Communication Aid Manufacturer's Association (CAMA). CAMA hosts workshops in various parts of the United States throughout the year, highlighting the products of various AAC device manufacturers. They can be reached at (800) 441-2262; Web site http://www.accproducts.org; E-mail: cama@northshor.net

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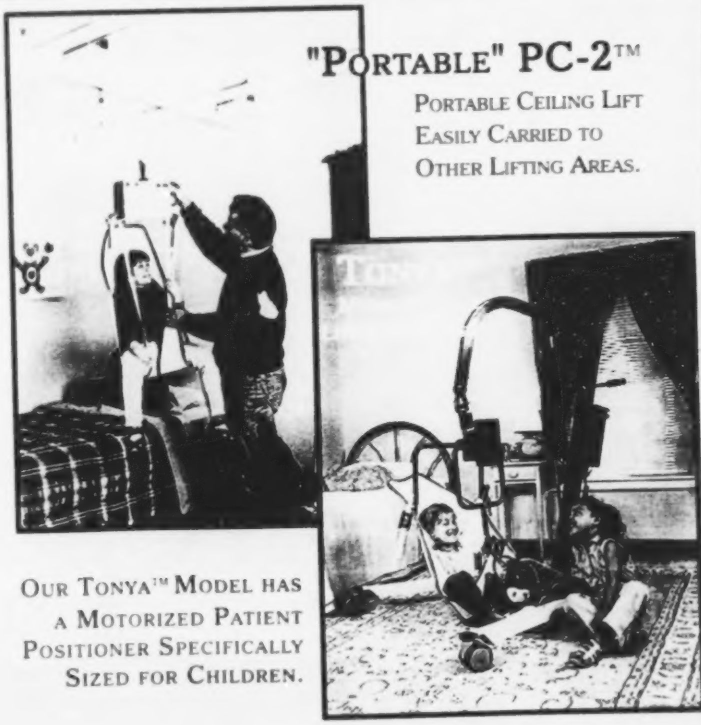

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Circle #60

MEDICAL RESEARCH UPDATE

Compiled by David Chamalian

TYPE II DIABETES AND CHILDREN: DETECTION AND PREVENTION

Type II diabetes, once thought to be rare in children, is being diagnosed more often in children and adolescents. Health experts attribute this rise to growing obesity rates in kids and teens. As a result, an eight-member panel of experts, convened by the American Diabetes Association, recommends testing overweight children—those at more than 120 percent of their ideal weight for height. The panel also added recommendations to include education for children on how to manage their disease: monitoring blood glucose levels; tips on daily exercise; and dietary recommendations. Further suggestions from the panel members include regular screening for complications of diabetes, such as eye problems, high blood pressure, and kidney malfunctions. The recommendations were published in the March 2000 issue of Pediatrics.

JUVENILE ARTHRITIS AND RESISTANCE EXERCISE: A BENEFICIAL MATCH

Nadine Fisher, EdD, revealed in her research that children who have juvenile arthritis who participated in an individualized resistance-exercise program showed as much as a 200 percent improvement in their ability to function. In addition, the results showed a marked drop in their pain, disability, and use of medications. "We expected to see a change in the disease with exercise," Fisher said, "but we didn't expect to see so much. Everybody showed tremendous physiological improvement—better strength, endurance, and even better aerobic capacity...Everyone had less pain." An accompanying investigation, done by Jaya Venkatraman, Phd, reveals the reason for such positive results: the exercise induced a change in immune response. Nadine Fisher, EdD, is assistant professor of occupational therapy and rehabilitation medicine, and Jaya Venkatraman, PhD, is associate professor of nutrition. Both are affiliated with the University at Buffalo. Results were presented at a joint meeting of the American College of Rheumatology and the Association of Rheumatology Health Professionals.

NEW SURGERY AVAILABLE TO AID BREATHING FOR PEOPLE WITH QUADRIPLEGIA

Abbot J. Krieger, MD, has discovered a surgical procedure to regenerate the phrenic nerve (which stimulates the diaphragm to move the lungs) and allow people to breathe on their own. The procedure, which has been performed successfully on six people, involves grafting living intercostal (between the ribs) nerves into the dead or damaged phrenic nerve. After approximately six months, nerve regeneration occurs, and the new nerves assume control over the electrical functions of the phrenic nerve. A pacemaker is also inserted to help the fused nerve send the correct "breathe" signal to the brain. "Breathing through a ventilator wears on the body and makes quadriplegics more susceptible to fever, infections, and pneumonia—the primary cause of death in quadriplegics," says Dr. Krieger. "This procedure eliminates the brute force of the ventilator and reproduces the smoothness of the natural breathing process, thereby prolonging the life span of many quadriplegics." The procedure was presented at the Congress of Neurological Surgeons 49th Annual Meeting.

PSYCHIATRIC DRUG PRESCRIPTIONS ON A SHARP RISE AMONG YOUNG CHILDREN

In the period between 1991 and 1995, researchers have found a dramatic increase in the number of preschool children taking stimulants, antidepressants, and other psychiatric drugs. Some of the drugs cited in the study were methylphenidate, the generic form of Ritalin®; clonidine, a blood pressure drug that treats insomnia associated with attention disorders; and Prozac® and Zoloft®, both antidepressants. The assumption among researchers is that the increase has continued since 1995.

What is troubling about the results of this study, researchers say, is that data on the safety and efficacy of these medications in preschoolers just do not exist. "We don't have any benchmarks to know if this is or is not a problem," says Dr. Julie Magno Zito, associate professor at the University of Maryland and lead author of the study. Dr. Zito and her colleagues report that few of the drugs are approved by the Food and Drug Administration for use in treatment of children under 5.

Experts are also troubled by the lack of research on how these drugs affect brain development. Says Dr. Joseph Coyle, chairman of psychiatry at Harvard Medical School, "These [drug] interventions are occurring at a critical time in brain development, and we don't know what the consequences are."

Clarification: In last month's column, we published an update on neurotransmitter disorders. In it we stated, "The result [of lack of information about and rarity of neurotransmitter disorders] is that many children may remain misdiagnosed and improperly treated." We would like to clarify this statement as follows: "The result is that many children may remain undiagnosed and potentially untreated."

Correction: Under the same heading, we printed the incorrect Web site for the Pediatric Neurotransmitters Disease Association. The correct Web site is http://www.pndassoc.org. We regret the errors.

EP

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POINT

On January 25, 2000, the National Council on Disability (NCD) issued its independent analysis of federal enforcement of civil rights laws. The report, entitled, "Back to School on Civil Rights: Advancing the Federal Commitment to Leave no Child Behind" looks at more than two decades of monitoring and enforcement of compliance with the Individuals with Disabilities Education Act (IDEA).

According to its mission statement,

> "The NCD is an independent federal agency making recommendations to the President and Congress on issues affecting 54 million Americans with disabilities. NCD is composed of 15 members appointed by the President and confirmed by the US Senate.
>
> The NCD's overall purpose is to promote policies, programs, practices, and procedures that guarantee equal opportunity for all individuals with disabilities, regardless of the nature or severity of the disability; and to empower individuals with disabilities to achieve economic self-sufficiency, independent living, and inclusion and integration into all aspects of society."

In its report, the NCD reveals some startling information. The NCD has found that "federal efforts to enforce the law over several Administrations have been inconsistent, ineffective, and lacking any real teeth." We have excerpted some of the major findings from the report's Executive Summary. (Following this excerpt is the response by Judith Heumann, assistant secretary, Office of Special Education & Rehabilitative Services, US Department of Education.)

BACK TO SCHOOL ON CIVIL RIGHTS: ADVANCING THE FEDERAL COMMITMENT TO LEAVE NO CHILD BEHIND

In the more than two decades since its enactment, IDEA implementation has produced important improvements in the quality and effectiveness of the public education received by millions of American children with disabilities. Today almost six million children and young people with disabilities ages 3 through 21 qualify for educational interventions under Part B of IDEA.

As significant as the gains over time are, they tell only part of the story. In the past 25 years, states have not met their general supervisory obligations to ensure compliance with the core civil rights requirements of IDEA at the local level. Children with disabilities and their families are required far too often to file complaints to ensure that the law is followed. The Federal Government has frequently failed to take effective action to enforce the civil rights protections of IDEA when federal officials have determined that states have failed to ensure compliance with the law.

FINDINGS:

- Every state was out of compliance with IDEA requirements to some degree.
- Notwithstanding federal monitoring reports documenting widespread noncompliance, enforcement of the law is the burden of parents who too often must invoke formal complaint procedures and due process hearings. Many parents with limited resources are unable to challenge violations successfully when they occur.
- The Department of Education has made very limited use of its authority to impose enforcement sanctions such as withholding of funds or making referrals to the Department of Justice, despite persistent failures to ensure compliance in many states.
- More than half of the states failed to ensure compliance in five of the seven main compliance areas.
- 90 percent had failed to ensure compliance in the category of general supervision.
- 88 percent failed to ensure compliance with the provision that requires schools to promote the appropriate transition of students with disabilities to work or post-secondary education.
- 80 percent of states failed to ensure compliance with the laws free appropriate public education requirements.
- 78 percent failed to ensure compliance with the procedural safeguards provision *[defined as parental rights to examine records, to obtain independent educational evaluations, to receive prior notice if a service is refused, to consent prior to any evaluations of services, to be granted an impartial due process hearing, to be allowed an administrative appeal and civil action in state or federal court, and to be afforded confidentiality.]*
- 72 percent failed to ensure compliance with the placement in the least restrictive environment provision.
- Only one enforcement action involving a sanction (withholding) *[of federal funds]* and five others involving imposition of "high risk" status and corrective action as a prerequisite for receiving further funds have been taken. The only withholding action occurred once for a temporary period and was overruled by a federal court.

RECOMMENDATIONS:

- Congress should amend IDEA to create a complaint-handling process at the federal level.
- Congress should amend IDEA to provide the Department of Justice with independent authority to investigate and litigate cases brought under IDEA.
- Congress should include in the amendment that the Department of Education and the Department of Justice shall consult with students with disabilities, their parents, and other stakeholders to develop objective criteria for defining 'substantial noncompliance.'
- The Department of Education should establish and use national compliance standards and objective measures for assessing state progress toward better performance outcomes for children with disabilities and for achieving full compliance with Part B.
- The Department of Education should consult with students with disabilities, their parents, and other stakeholders in developing

and implementing a range of enforcement sanctions that will be triggered by specific indicators and measures indicating a state's failure to ensure compliance with Part B.

- Regular and special education teachers in many states are frustrated by the mixed messages regarding compliance from school administrators, local special education directors, state oversight agents, school district attorneys, and federal oversight agents. Teachers ultimately bear the responsibility to implement interventions and accommodations for students with disabilities, often without adequate training, planning time, or assistance. They must function within an educational system that often lacks adequate commitment, expertise, or funding to deliver appropriate services to every child who needs them.
- Pervasive and consistent noncompliance with IDEA is a complex problem with often dramatic implications on a daily basis for the lives of children with disabilities and their families. Too many parents continue to expend endless resources in confronting obstacles to their child's most basic right to an appropriate education, often at the expense of their personal lives, their financial livelihoods, and their careers. Students are frustrated—their skills undeveloped and their sense of belonging tenuous.
- Congress and the President should appropriate [funds for] free or low-cost legal advocacy services to students with disabilities and their parents through public and private legal service providers.
- The Department of Education should give priority support to the formation of a comprehensive and coordinated advocacy and technical assistance system in each state.
- Lawyers should be available at every state Parent Training and Information Center, and a backup system should be established with legal materials, training, and support for attorneys who are working on IDEA cases. Training in culturally sensitive dispute resolution and the accommodation of multiple language needs and communication styles should be implemented.

To date, federal compliance-monitoring and enforcement efforts have not fully dealt with the root causes of widespread noncompliance, and children with disabilities and their parents have suffered the consequences. NCD calls on Congress and the President to work together to address the inadequacies identified by this report so that children and families will have an effective and responsive partner in the Federal Government when they seek to ensure that IDEA's goals of enhanced school system accountability and improved performance outcomes for students with disabilities move from the language of the law to the reality of each American classroom.

Excerpted from "Back to School on Civil Rights: Advancing the Federal Commitment to Leaving no Child Behind" Report by the National Council on Disability, January 25, 2000. The full report can be obtained from the NCD Web site, http://www.ncd.gov.

COUNTERPOINT

THE DEPARTMENT OF EDUCATION RESPONDS

Judith E. Heumann, assistant secretary, Office of Special Education & Rehabilitative Services, US Department of Education, has been kind enough to make available the statement issued by the Department of Education in response to the NCD Report.

"The National Council on Disability report draws our attention to how this important federal law has been monitored and enforced. We concur with one of the major premises of this report: parents should not bear the burden of enforcement just to get their children an education. Families should be partners with schools, states and the Department of Education in the effective implementation of the law.

Since IDEA was implemented, more than six million infants, toddlers, and children with disabilities are provided early intervention and special education services. The [NCD] report draws critical attention to the fact that not all children with disabilities in America receive an appropriate education. It is also important to recognize that there are a growing number of states, schools, and districts that are aggressive in ensuring both compliance and the provision of quality services for children.

The report accurately indicates that there are compliance problems throughout the country. These problems vary by state in severity, complexity, pervasiveness, and longevity.

In 1998, the Department of Education reinvented its system for monitoring state compliance with IDEA after extensive input from advocacy organizations and members of the disability community, including some of our strongest critics.

We have already seen increased involvement of parents,

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LEGISLATIVE UPDATE

by Julie Keys

This month, we introduce a new feature highlighting current activities in Washington which impact the special needs community. This installment has been provided by Family Voices' National Communications/Development Coordinator, Julie Keys. Family Voices is a national, grassroots clearinghouse for information and education concerning the healthcare of children with special health needs. As their mission describes, "Family Voices follows public and private sector healthcare changes affecting our children with special healthcare needs."

"YOUR VOICE COUNTS"

The past few months have seen increased activity around important issues for our children and families, including healthcare and education and some bills before Congress that can make a big difference in our children's lives.

Family Voices and Brandeis University recently released a report: "Your Voice Counts!" the Family Partners Project Survey. The survey is the first of its kind, designed, distributed, and analyzed by families and researchers. We surveyed over 2,200 families in 20 states who have children with special healthcare needs. We found that families across the country report tremendous challenges in accessing healthcare information for their children. While some families are faring well, many experience difficulty in finding skilled providers and getting necessary information. For example:

- ☆ Only 60 percent of the families gave their plan's benefits a good or excellent rating in meeting their child's health needs.
- ☆ Many mothers provide more than 20 hours/week of healthcare services at home to their child.
- ☆ Nearly two-thirds of the families had reduced their hours of employment and/or stopped working altogether because of their child's health.
- ☆ Approximately 37 percent of the families had contacted their health plan regarding a problem, and 42 percent of those families were not satisfied with the resolution.
- ☆ Families who have children with behavioral health diagnoses or complicated health conditions report the most problems in obtaining adequate health care for their children.

The survey reflects a picture of families experiencing multiple demands and stresses. The results of the survey, reinforced by stories we have heard for years from families around the country, should help policymakers realize how crucial it is that all families receive more help than they are now receiving, especially families with children with special healthcare needs.

To that end, Family Voices made some policy recommendations to Congress:

- ☆ Pass legislation to make Medicaid available to all children who need specialized services and allow them access to the comprehensive benefits packages provided by Medicaid. This will help guarantee an adequate health coverage package and reduce out-of-pocket expenses paid by families who currently rely on less adequate private coverage. This access can be through a sliding fee scale, or other buy-in program.
- ☆ Legislate mandates and funding to support Family-to-Family Health Information Centers in each state. These Centers will provide families across the country direct access to trained, experienced families who can help them find the information they seek—how programs work, how to get access to them, where to find support and how to resolve other problems in caring for their children with special healthcare needs.
- ☆ Make funding available to measure the quality of care that our children with special healthcare needs receive.
- ☆ Pass a Managed Care Patient's Bill of Rights that will protect our children with special health care needs.

While we had hoped that Congress was listening, little did we know how quickly we would be heard! About a month after the briefing, Senator Charles Grassley (IA) and Senator Edward Kennedy (MA) introduced the Family Opportunity Bill of 2000. This bill has three parts:

1. Make a Medicaid buy-in available to families with children under 21 if their children meet the disability determination established by SSI (supplemental security income) but the child is ineligible due to the parents income.

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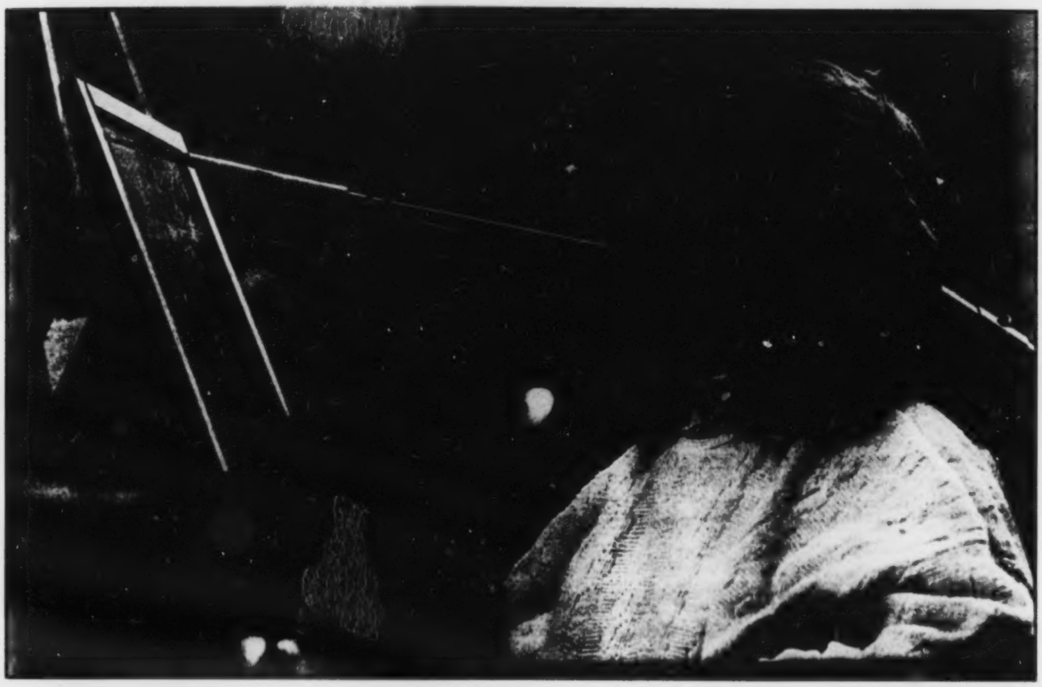

The Joy of Independence

Spring Time by Amy Neubauer

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To find out more about the compassionate and caring services we provide for special children throughout the world, please call Debra Flanders in Admissions at 603-547-3311, ext. 235.

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NAIS

Circle 496

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2. Make a Medicaid buy-in available for families whose children will meet the disability determination if they do not receive the services available under Medicaid.

3. Establish Family-to-Family Health Information Centers in each of the fifty states through a competitive grant process.

The families in our survey whose child's primary plan was paid by Medicaid were more satisfied and had fewer problems than families in private health plans. The advantages of Medicaid were: the broad range of services covered under Medicaid, and fewer out-of-pocket expenses. For many parents, having a child with special healthcare needs has a significant family impact, affecting their finances, jobs, and time spent providing direct healthcare.

This bill, as it was written at press time, will help families maintain their children in their own homes and communities with the support of services offered under Medicaid. This will relieve many families who have had to make the impossible choice of placing their children in an institutional setting or placing them in foster care to make sure their child receives the services he or she needs.

Families and parent advocates should keep an eye on this bill. No doubt it will undergo some changes before it is voted on, and we need to make sure that the supports and services our children need stay intact. For a copy of the Executive Summary of the Family Partner's Survey, the Report to Families, or a packet of Fact Sheets of survey results on specific subjects, contact Nora Wells at the Family Voices office in Boston, (617) 236-7210, or E-mail: nwells@fcsn.org. **EP**

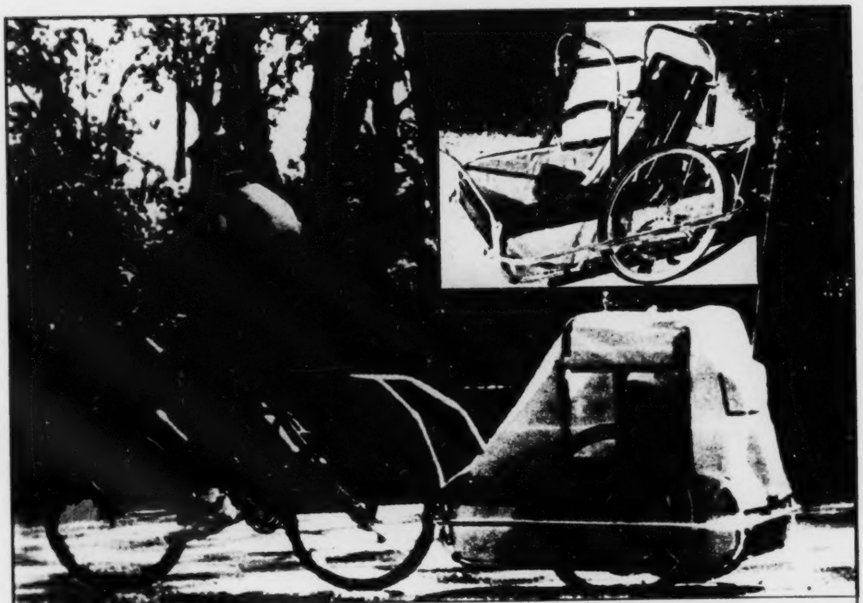
In other legislative news:

1. **Employment:** The Work Incentives Improvement Act (WIIA) is now signed into law. Now we must make sure our states implement the law. This legislation allows people with disabilities to maintain their Medicare or Medicaid coverage when they go to work. It also includes provisions that allow people with disabilities who are still working and are not yet "sufficiently disabled" to qualify for Medicaid to buy into the program. Finally, the bill reforms the training system for people with disabilities.

2. **Education:** The Educational Excellence for All Children Act (S. 1180, H. R. 1960), formerly the Elementary and Secondary Education ACT (ESEA), includes several components that will impact students in special education, including: discipline, supports and services; and equality in education.

3. **Legal:** The Hate Crimes Prevention Act of 1999 (S. 622 / H.R. 1082) will be revisited during the second session of the 106th Congress. This can help individuals with disabilities who are too often vulnerable for hate crimes. It will be important for advocates to keep an eye on this and ensure that individuals with disabilities remain protected as the bill is further developed.

Julie Keys is the National Communications/Development Coordinator for Family Voices. She is also Project Director of KASA, the Kids As Self Advocates project, a national organization of youth with special healthcare needs speaking on behalf of themselves. You can reach Julie at her office in Chicago at (312) 222-1980, or E-mail her: Julie@fvkasa.org.



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COUNTERPOINT

continued from page 83

advocates and other state agencies in the monitoring process. We anticipate this will result in a greater likelihood of systemic changes which, in turn, will have a positive impact on better results for children with disabilities.

With a more collaborative overall process that encourages states to address deficiencies, we have already seen positive results. As a direct result of the new system, one state has revised its funding formula removing incentives for restrictive placements, and another state has revised its monitoring system to better ensure that services were received and rights were provided at the local level.

This administration has used the enforcement tools and sanctions at its disposal, including corrective action plans, special conditions on grants and multi-year compliance agreements. In addition, we also have the option to withhold state funds, which we exercised with the state of Virginia.

In 1997, Congress strengthened these enforcement options. As a result, we currently have ongoing discussions with the Department of Justice concerning our findings should we find it necessary to utilize the referral option for states.

The IDEA is designed to make sure that children with disabilities have an equal opportunity to meet challenging academic standards, to learn, to stay in school, to graduate and to move on to postsecondary education and the world of work.

This administration takes seriously the findings of this report and will thoroughly review its recommendations. We are always refining our methods for holding states accountable for the education of children with disabilities.

We appreciate all the work put into this product and look forward to working collaboratively with the NCD to improve the quality of education for children with disabilities across the country." **EP**

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NATIONAL TOURETTE SYNDROME ASSOCIATION

OUR MISSION: IDENTIFY THE CAUSE, FIND THE CURE, CONTROL THE EFFECTS OF TOURETTE SYNDROME, AND SERVE EVERYONE AFFECTED.

The Tourette Syndrome Association (TSA) is a national, nonprofit voluntary health organization with over 50 chapters and over 30 support groups. Members include people with Tourette syndrome (TS), their relatives, and other interested, concerned supporters. TSA was established in 1972 when a handful of New Yorkers with family members who had TS came together to support one another and raise awareness.

As a result of TSA's medical and public education efforts, the gap between symptom onset and a diagnosis has narrowed. Today families are diagnosed more quickly than in the past, when it could take 10 years or more.

What is Tourette syndrome?

The Gilles de la Tourette syndrome is an inherited, chronic neuropsychiatric disorder—a long-term problem affecting the nerves and those parts of the brain that govern behaviors. It is characterized by the presence of tics (repeated involuntary contractions of groups of muscles) that cause unintentional movements (motor tics) and unintentional sounds (phonic tics). In addition to tics, children with TS often have a variety of behavioral or psychiatric problems.

Tourette syndrome affects between 1 and 10 out of every 10,000 people worldwide, and is three times more common in males than in females. It usually begins in childhood, often between ages 6 and 7.

TSA in action

National TSA remains the primary source of accurate and up-to-date information about TS, its treatment, relevant resources, and consumer services. TSA publishes a newsletter; maintains a crisis hotline; and produces valuable information for people with TS and their families, medical and allied professionals, educators, and legislators.

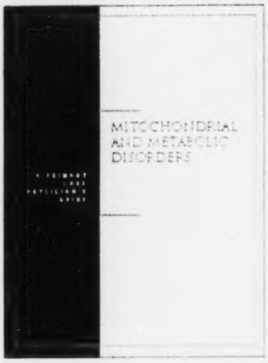
TSA also:

- offers direct help to families in crisis through its information and referral service;
- organizes workshops and symposia for scientists, clinicians, and others working in the field of TS;
- promotes public awareness and understanding;
- maintains a database of allied professionals including social workers, psychologists, nurses, educators, etc.;
- sponsors the Tourette syndrome Brain Bank Program, involving the collection of needed tissue for scientific research;
- organizes and assists local chapters and support groups throughout the US and the world;
- serves tens of thousands of members in the US and abroad;
- increases the knowledge and sensitivity to TS among healthcare professionals through exhibits, the dissemination of literature, and organization of national conferences;
- develops and maintains state-by-state lists of doctors who can diagnose and treat TS; and
- represents the interests of members to the government on critical policy issues, including orphan drugs, health insurance, education and employment.

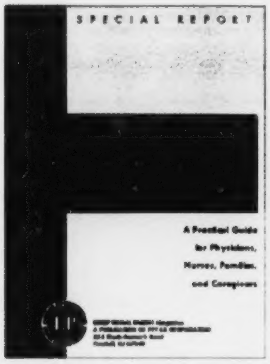
continued on page 90

Special Reports

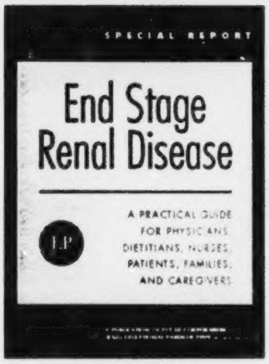
We are pleased to announce that the following Special Reports are now available through Exceptional Parent Library, except as noted.


MITOCHONDRIAL
AND METABOLIC
DISORDERS

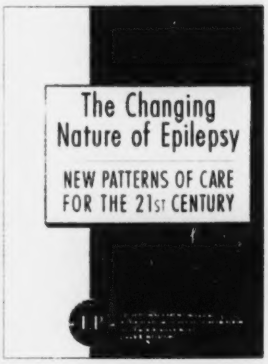
EP300MC
Mitochondrial and Metabolic Disorders–A Primary Care Physician's Guide


SPECIAL REPORT
A Practical Guide
for Physicians,
Nurses, Families,
and Caregivers

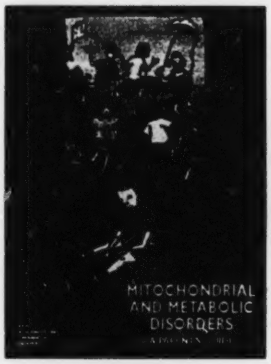
EP410CP
Positive Perspectives for Cerebral Palsy


SPECIAL REPORT
End Stage
Renal Disease
A PRACTICAL GUIDE
FOR PHYSICIANS,
DIETITIANS, NURSES,
PATIENTS, FAMILIES,
AND CAREGIVERS
EP

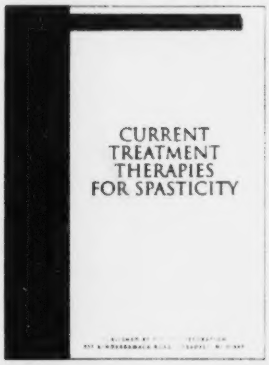
EP400RD
End Stage Renal Disease-A Practical Guide For Physicians, Dietitians, Nurses, Patients, Families, and Caregivers


The Changing
Nature of Epilepsy
NEW PATTERNS OF CARE
FOR THE 21ST CENTURY
EP

EP530EP
The Changing Nature of Epilepsy–New Patterns of Care for the 21st Century* available by 12-1-99


MITOCHONDRIAL
AND METABOLIC
DISORDERS

EP310MC
Mitochondrial and Metabolic Disorders - A Parents' Guide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ORGANIZATIONAL SPOTLIGHT

continued from page 88

Client services

TSA develops and disseminates educational material to individuals, professionals, and agencies working in the fields of healthcare, education, and government; coordinates support services to help people and their families cope with TS; funds research that will ultimately find the cause of and cure for TS and, at the same time, lead to improved medications and treatments.

TSA oversees a Permanent Research Fund, which provides grants for research into unlocking the mysteries of TS.

Tourette syndrome affects between 1 and 10 out of every 10,000 people worldwide, and is three times more common in males than in females. It usually begins in childhood, often between ages 6 and 7.

Membership in TSA

Membership benefits include:

- joining other families at meetings to discuss common problems and offer mutual support; and
- supporting our efforts to increase public understanding, achieve early identification, and improve treatments.

For almost a decade, TSA has kept its annual dues at $45. Families with TS who cannot afford dues need only inform us, and they will receive all the benefits of membership. Members in good standing receive a quarterly newsletter, discounts at conferences, discounts on publications, and much more. **EP**

The Tourette Syndrome Association, Inc., has an extensive list of publications and videotapes available. Full descriptions are contained in the *TSA Catalog of Publications and Films*. Write for a free copy to:

Tourette Syndrome Association, Inc.
42-40 Bell Blvd., Bayside, NY 11361-2820; Phone: (718) 294-2999
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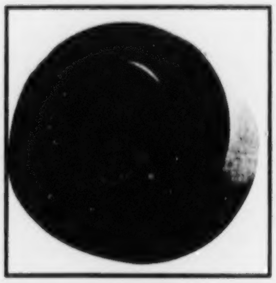
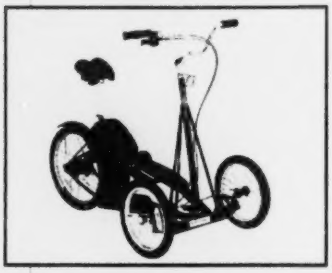
STEP-BY-STEP COMMUNICATOR 75 WITH LEVELS



The Step-by-Step Communicator 75 with Levels is a combination touch switch and direct-selection communicator designed for use by individuals with physical, cognitive, and communication disabilities. The communicator is activated by pressing the switch surface and offers 75 seconds of recording time. This device allows multiple series of messages to be recorded on different levels. Using the levels, messages can be stored in categories or organized so that a series of messages pertaining to a specific activity can be stored on its own level. This communicator has a black base and is available in red, pink, yellow, green, blue, purple, and black.

AbleNet®, Inc., 1081 Tenth Ave., Minneapolis, MN 55414-1312; (800) 322-0956



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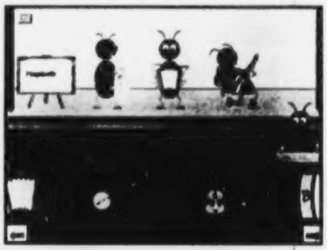
LET'S START™ LEARNING BOOKS

Let's Start™ Learning Books is a series of interactive board books for assisting children with cognitive disabilities to learn basic skills such as telling time, differentiating between big and small, learning shapes, and learning numbers. Each book includes materials for hands-on activities, such as stamping, placing stickers, and marking on erasable surfaces with erasable markers to reinforce skills taught in the books. Titles in this series are each sold individually and include Let's Start™ Alphabet, Let's Start™ Numbers, Let's Start™ Shapes, Let's Start™ Learning: What's the Time?, and Let's Start™ Learning: Big or Small?

Advantage Publishers Group, Silver Dolphin™ Books, 5880 Oberlin Dr., Ste. 400, San Diego, CA 92121; (800) 284-3580; E-mail: apgcuserv@advmkt.com; Web site: http://www.advantagebooksonline.com

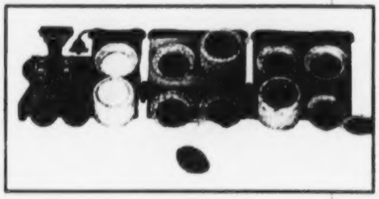
BEETLES BY SEMERC



Beetles is a cause and effect computer program designed for use by students with cognitive and developmental disabilities. Available for computers running Windows®. The Beetles play songs using the choice of 20 instruments selected by the user. The program is accessible by mouse, touch screen and switch, and enables the user to give each Beetle a different instrument and hear the group play a song. The user can then change instruments and hear the song again. The program provides 55 ready-made songs in a variety of styles, including American, folk, classic, modern, nursery, and Christmas. The program uses standard MIDI files, enabling other songs to be downloaded to customize the program.

ProMedia, Inc., 57 Lakeview Ave., Clifton, NJ 07011; E-mail: Tom@promediaNJ.com; Web site: http://www.promedia-Semerc.com

TACTILE TRAIN



The Tactile Train is a visual and tactile activity designed for use by children with visual impairments. The wooden board is printed with a colorful train. Each of the train's windows and wheels offers a space with a specific texture; the accompanying knobs fit into the spaces and textures on the board. This game invites children to explore and discriminate between ten different textures, ranging from sandpaper rough to velvet softness.

Guidecraft USA, PO Box 324, Industrial Plaza, Garnerville, NY 10923-0324; (800) 544-6526

The ABLEDATA database of assistive technology and rehabilitation equipment contains information on more than 25,000 products for persons of all ages who have a physical, cognitive, or sensory disability. Products are chosen for this page by the ABLEDATA staff based on their specific applicability to or design for children who have disabilities. ABLEDATA, operated by Macro International Inc., is funded by the National Institute on Disability and Rehabilitation Research under contract number HN-96015001.

For more information on these and other assistive devices, or to submit product information for the database (and possible inclusion on this page), contact: **ABLEDATA, 8401 Colesville Rd., Ste. 200, Silver Spring, MD 20910; (800) 227-0216 or (301) 608-8998 (voice); (301) 608-8912 (TTY); (301) 608-8958 (fax); Web site: http://www.abledata.com.**

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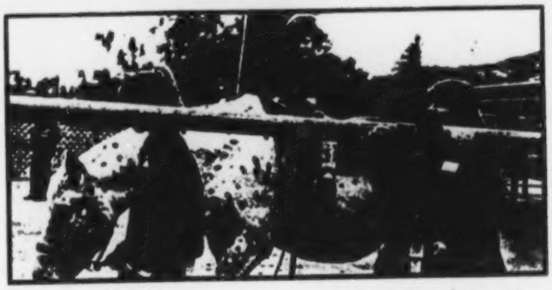

Brandon Meachare, 6, goes for a ride. Brandon has autism, and according to his mom, Kathy, he is very loving and caring toward others. He enjoys puzzles, watching Blue's Clues on TV, and riding his bike outdoors. He is mainstreamed in the first grade at Whittier Elementary School and is doing very well. Brandon and his mom live in Hemet, CA, with a pet rat, Freckles.

Gabrielle Iannizzi celebrates her sixth birthday with her dad, **Corrado,** and 3-year-old brother, **Anthony**. Gabrielle has cerebral palsy and attends United Cerebral Palsy of Brooklyn, NY. Gabrielle enjoys going to school and learning, according to her mom, Nancy. Shopping malls, going for walks, and listening to music are also among her favorite things. She always has a smile on her face. Gabrielle lives with her family in Brooklyn, NY.

Gone fishin'! **Ryan Patrick Schadt**, 5, has Angelman syndrome. He attends full-time special education classes near his home in West Peoria, IL, where he lives with his parents, Cheryl and Terry, and brother, Matthew, 6. Ryan loves water play, wrestling with his dad and brother, and playing with the two family cats. He always has a smile and a hug for everyone, according to his mom.

Would you like to share a favorite candid snapshot or slide of your child and/or family with other readers of ***Exceptional Parent?*** Send it to: Readers' Photos, *Exceptional Parent*, 555 Kinderkamack Road, Oradell, NJ 07649-1517. (Please do not send originals or "one-of-a-kinds" as we regret that **photos cannot be returned.)**

Circle #18

The Smotherman children pile into a chair! (From left to right): **Briana**, 8, **Jenna**, 6, **Brenden**, 4, and laying across them is their baby brother **Jacob**, 2, whom they adore. Jacob has spastic quadriplegic cerebral palsy, microcephaly (small head), seizures, cortical visual impairment, kidney disease, reflux, sleep apnea, and global developmental delays. Jacob, who attends Early Intervention at Heritage Elementary School, loves listening to music, swinging in his swing, and being tickled. His favorite activity is being with his parents, Rebecca and Joseph, and siblings. The family lives in Milford, MI.

Erin (left) and **Jessica Cox** are 5-year-old twins who just love to cheer for their favorite football team, BAMA! Jessica has spastic quadriplegic cerebral palsy, and she receives occupational, physical, and speech therapy at the Prattville Kindergarten Opportunity Center. She also attends regular kindergarten. Both sisters love country music, especially Travis Tritt. Jessica and Erin live with their parents, Jeff and Kay, in Prattville, AL.

Amy Lynn Regan, 9 months, is all decked out! Amy has Down syndrome and receives twice-weekly physical and occupational therapy at Early Intervention. Amy loves toys that have lights and sounds, and according to her mom and dad, Lisa and Leo, she lights up, too! Amy lives in Brockton, MA, with her parents, sister Alyssa, 14, and brothers Leo Jr., 11, and Arthur, 3.

Now on the Web! *We will now be including Familiar Faces and Children's Page on our Web site, www.eparent.com. Please send us your photographs with the understanding that doing so gives Exceptional Parent permission to put the photos on the Exceptional Parent Web site, exactly as they appear in the magazine and with the same text.*

On a separate sheet of paper, write your child's full name, age at the time the photo was taken, address and daytime phone number. Please identify everyone in the photo. If you like, you can also write a few sentences about your child. Then look for a familiar face in an upcoming issue!

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Circle #78

Osteogenesis Imperfecta

by Priscilla Wacaster, MD

Osteogenesis imperfecta (OI) is a genetic disorder of collagen, the protein that gives strength and structure to bones and other connective tissues. The bones in people who have OI have either a weakened form of collagen or too little normal collagen. This causes their bones to fracture with little or no trauma. A person who has OI might have as few as half a dozen or as many as several hundred fractures in a lifetime. Between 20,000 and 50,000 people in the United States have OI.

Q How is OI diagnosed, and how do I know what type of OI my child has?

A OI is often diagnosed when fractures occur and a physician observes other clinical features of OI. Two laboratory tests may help confirm the diagnosis: a collagen test and a DNA test. Neither test is 100 percent accurate; some children with OI may have negative test results. The two severe types of OI are often diagnosed before birth, when ultrasound examinations reveal fractures, bone shortening, and other bone abnormalities.

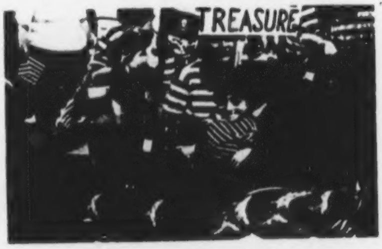
Four types of OI have been described, representing wide variation in symptoms and severity. The types are distinguished based on their clinical features; that is, stature, bone deformity, fracture frequency, and other symptoms. Because the definitions rely on subjective observations, determining the type is not always clear-cut. Some people do not fit into any of the four types, so it is possible that even more types may be defined in the future. In many cases, these diagnostic tools cannot pinpoint the type of OI the child has with 100 percent accuracy.

Type I: This is the mildest type of OI. People with this form may have only a handful of fractures throughout their lifetime. They will be normal or near-normal height and have little or no bone deformity. Children with Type I OI seldom have fractures at birth; they are often not diagnosed with OI until they have had one or more fractures in infancy or early childhood.

Type II: This is the most severe type of OI. Babies born with this type often have respiratory problems in addition to very fragile bones, and they may die at or shortly after birth.

Type III: People who have this severe form of OI have many fractures, sometimes several hundred in a lifetime. They will be very short in stature and experience other health problems caused by bone deformity. Children who have Type III OI are often born with fractures and bone deformity, and they may show evidence of fractures that occurred before birth.

Type IV: This type usually falls somewhere between Type I and Type III in severity. People who have Type IV OI are often smaller than average, have numerous fractures, and have mild to moderate bone deformity. Whereas people with the other types of OI tend to have a bluish color in the sclera (whites of the eyes), people with Type IV often have sclera that are white or near-white.



Sean Stephenson, (above) who has OI, enjoys participating in a parade.

Q Besides fragile bones, what other health problems might my child have?

A Although fragile bones are the hallmark of OI, the disorder affects the entire body. Other symptoms include: "loose" joints, low muscle tone, a tendency toward easy bruising, translucent skin, a barrel-shaped rib cage, excessive sweating, and blue sclera.

Spinal curvature (scoliosis) and rib cage deformity can lead to respiratory problems.

Many people who have OI will develop hearing loss, often beginning in their 20s and 30s, as the disease affects the bones in the ears.

Some people with OI have brittle, discolored teeth, a condition known as dentinogenesis imperfecta.

Q What can I expect for my child as he or she grows?

A Knowing the type of OI your child has can help your family understand the disorder and provide a general idea of what to expect in the future. Two people with the same type of OI, however, may have very different experiences with fractures and mobility. For example, one person with mild OI might have only four or five fractures throughout his

Ask the Doctor addresses issues of concern to our readers and is usually coordinated on a monthly basis by David Hirsch, M.D., a pediatrician and member of *Exceptional Parent's* Editorial Advisory Board. Dr. Hirsch is a partner in Phoenix Pediatrics, Ltd., in Phoenix, Arizona, and specializes in treating children who have developmental disabilities and chronic illnesses.

Parents should review any suggestions made in this column with the appropriate professionals. Mention of specific products or medications illustrate suggestions and are not endorsements of any specific products.

Send questions to: **Ask the Doctor,** *Exceptional Parent,* 555 Kinderkamack Road, Oradell, NJ 07649-1517, or fax, (201) 634-6570.

or her lifetime and participate in sports with no ill effects, while someone else might have several dozen fractures and walk with crutches. One person with severe OI may use a walker, while someone else may use a wheelchair. The number of fractures and the need for surgery also vary widely, even among people with the same type of OI.

Rather than focusing on the type of OI, it is more useful to base future expectations on your child's abilities, strengths, and weaknesses. Your child's physician, physical therapist, and the other professionals on your healthcare and educational teams can work with your family to help your child function to the best of his or her ability. It is reasonable to expect children who have OI to become independent in all major life functions (self-care, locomotion, recreation, social interaction, and education) with the help of adaptive equipment, as needed. OI does not affect intellectual, mental, or emotional health. People who have OI can succeed in school, work, family, and social environments.

Life expectancy for people who have OI has not been clearly defined. In general, life expectancy for people with mild and moderate OI is average. Babies who have the most severe type of OI (Type II) may die before or during birth, in infancy, or in childhood, although some people who have Type II have survived into young adulthood. Life expectancy for people with Type III OI is affected by the severity of spine and chest deformities. Individuals may live into old age or succumb to respiratory infection in middle adulthood.

Q Is there anything we can do to prevent fractures?

A Fractures will happen no matter how careful you and your child are; they are simply a fact of life with OI. Fractures are often unpredictable. One day your toddler might fall down without injury, while the next day his or her leg might fracture during a diaper change. While some caution is called for, it is still important for your child to move, play, and interact with others as much as possible.

Babies who have OI should be handled gently. Pick the baby up with one hand firmly supporting the neck and head, and the other hand supporting the back, buttocks and legs. Be aware of the positioning of the arms and legs to avoid getting them caught in an awkward position. If your baby has severe OI, it may be helpful to use a pillow or foam pad to carry him or her. When changing a diaper, lift under the baby's buttocks rather than pulling on his or her ankles. A video and booklet describing how to care for infants and young children who have OI are available from the OI Foundation.

Kelly Petrolelle and Nicole Hofhine smile for the camera. Between 20,000 and 50,000 people in the United States have OI.

As your child grows, you will both learn what types of play and movement are safest. It is natural for your child to test his or her limits and abilities, and sometimes a fracture will occur as a result. Most people with OI say that they would rather experience life and experi-

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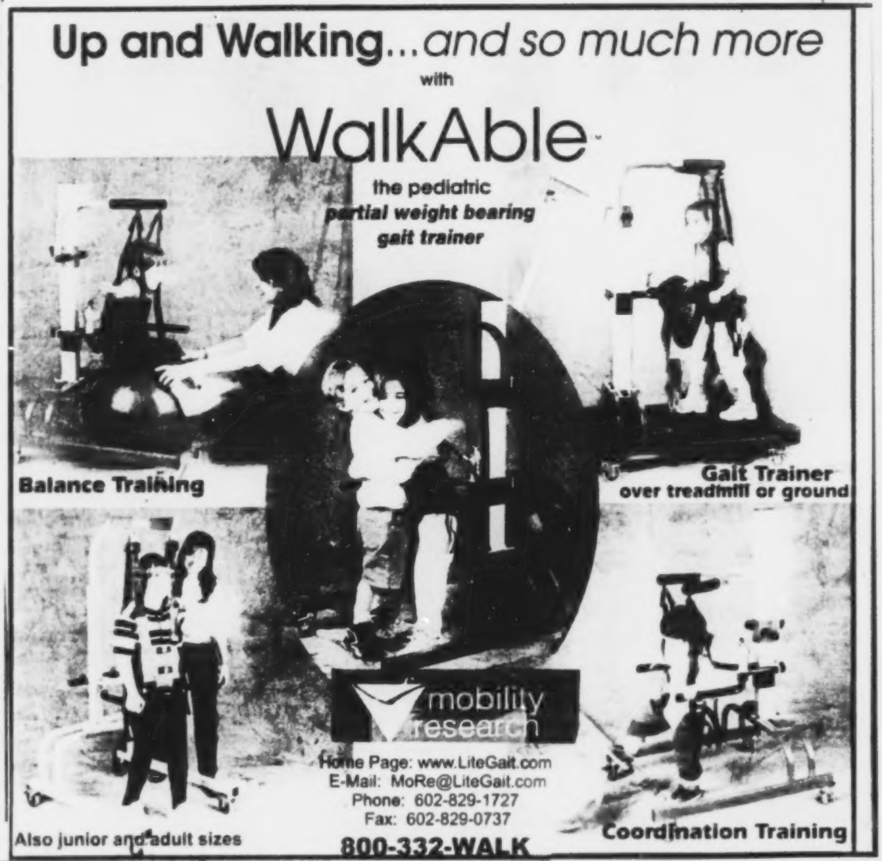

Circle #56

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continued from page 95

ment with their abilities, and thus risk fractures, than "sit on the sidelines." Active play and exercise may even help prevent fractures, because stronger muscles lead to stronger bones.

Q What type of doctor can provide the best care for my child?

A The OI Foundation maintains a physician referral database and may be able to refer you to a physician with experience treating OI. Because OI is a rare disorder, however, there may not be an experienced doctor in your area. In that case, a board-certified, knowledgeable, and compassionate pediatric orthopedist (a doctor who specializes in children's bones) is your best option. Your pediatrician or other families affected by OI may be able to recommend someone. The OI Foundation can provide you and your physician with the latest information on OI and refer your physician to OI experts for peer consultation.

Your child will also need to see a pediatrician regularly for immunizations and other routine care. You and your child may need to consult other medical professionals, such as a physical therapist or an ENT (ear, nose, and throat) specialist for hearing loss as the need arises.

Q How will OI affect my child's education?

A OI does not affect intellectual ability, and many children with OI excel in school. Under the federal Individuals with Disabilities Education Act (IDEA), all eligible school-aged children and youths with disabilities are entitled to receive a free appropriate public education in the least restrictive environment. By participating in all school activities with their peers, children with OI can experience both the intellectual challenge and social interaction they need to become successful adults.

Children with OI may need special accommodations or assistance to allow them to fully participate in school, and in many cases, public schools are required by law to provide this assistance. In addition to an assessment of architectural barriers, the need for adapted physical education, physical and occupational therapies, personal aides, assistive devices, and transportation should be considered. School personnel should be trained to deal with fractures or other medical emergencies that may occur at school.

These issues are best addressed by a team of people involved in the child's education, including parents,

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teachers, adapted physical education specialists, special education specialists, therapists, the school nurse, and, when appropriate, the child. By developing an Individual Education Plan (IEP), this team can plan for the student's success in all areas of education. A video and booklet showing how to integrate children into school activities, including physical education classes, are available from the OI Foundation.

Q How is OI treated?

A OI is treated primarily by managing fractures and promoting independence and mobility. Prolonged immobility can lead to muscle loss, weakness, and more fractures. Many orthopedists prefer to treat fractures with short-term immobilization in lightweight casts, splints, or braces to allow some movement as soon as possible after the fracture.

Many children who have OI undergo a surgical procedure known as "rodding," in which metal rods are inserted into the long bones to control fractures and improve deformities that interfere with function.

Physical therapy is appropriate for infants and children who have muscle weakness or motor skill delay when compared with same-age peers. Occupational therapy can help your child develop age-appropriate, fine motor skills and identify adaptive equipment that will allow your child as much independence as possible in daily living.

As a child with OI grows older, he or she will benefit from continued physical activity, such as adapted physical education and safe exercise. Swimming and aquatic therapy are particularly well suited for people with OI.

Various minerals and medications have been tested to determine if they strengthen bone in people with OI. Unfortunately, most of these substances have not been proven effective. Current research is investigating whether the bisphosphonate drugs, which are currently approved for use in postmenopausal osteoporosis, will also be effective in treating OI. They are showing some promise, but the final results are not available. There are a number of ongoing clinical trials of bisphosphonates that your child may be eligible for. Before enrolling your child in any clinical trial, it is vital to get information on the risks involved. The OI Foundation can provide information to guide you as you decide whether to involve your child in experimental procedures.

Q If we have more children, what is the risk that they will

continued on page 101

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continued from page 97

also have OI?

A OI is caused by a dominant genetic mutation. Most children with OI inherit the disorder from a parent. If you or your spouse has OI, there is a 50 percent chance with each pregnancy that the child will have OI. An affected child will have the same mutation, and therefore the same type of OI, as his or her parent. The disorder may not affect the child in exactly the same way it has affected the parent, however.

Approximately 25 percent of children with OI are born into families with no history of the disorder. This is usually due to a spontaneous dominant mutation that takes place in the sperm or egg prior to conception. In most of these cases, the risk that the parents will have another child who has OI is the same as for the general population (i.e., the risk is very small). Occasionally, a parent may be mosaic for a mutation; that is, a mutation that causes OI is present in a percentage of the parent's reproductive cells. In these cases, there is a slightly higher risk (2 to 4 percent) of having more than one child who has OI. Unaffected siblings of a child with OI are at no greater risk of having children with OI than the general population.

Q Will there be a cure for OI?

A Researchers are exploring gene and cell therapies that correct the genetic defect that causes OI. These therapies are still being studied and perfected in laboratory animals.

Q Where can I get the latest information on OI?

A The Osteogenesis Imperfecta (OI) Foundation is a national non-profit organization that can provide information on these topics and many others. The OI Foundation publishes fact sheets, brochures, videos, audiotapes, and books for people who have OI, their families, and medical professionals. In addition, the OI Foundation has staff and volunteers available to provide individualized responses to your specific questions. The organization can also link you with other families and individuals living with OI through support groups, online chat rooms, and national conferences. To contact the OI Foundation call (800) 981-2663; E-mail: bonelink@oif.org; or visit their Web site: www.oif.org. **EP**

Priscilla Wacaster, MD, is a family practice physician. She and her two children, ages 8 and 2, have Type I OI. Dr. Wacaster is a member of the Medical Advisory Council for the OI Foundation.

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Moving Right Along

Take a few virtual stops at these Web sites for information on mobility.

by Vanessa B. Ira

One of the most notable contributions of the Internet is how it has made travel much less stressful. Resources on the topics of travel and mobility, easily accessible from one's desktop, are plentiful and available from nonprofit and commercial sources. Families that have children or young adults with special needs can begin exploring such resources through the following Web sites:

Abledata.com (http://www.abledata.com/text2/whl_chil.htm) Abledata, a federally funded project, provides "information on assistive technology and rehabilitation equipment available from domestic and international sources to consumers, organizations, professionals and caregivers within the United States." Its Web site includes an invaluable and detailed source of information under the section called "Wheelchairs for Children." Sub-topics in the section include: Considerations in Wheelchair Selection; Wheelchair Components; Types of Wheelchairs and Wheelchair Alternatives; Funding Sources; Companies.

Rehabcentral.com (http://www.rehabcentral.com/communityhome.cfm) This site provides the resources you need to find rehabilitation products and assistive devices. Relevant sections here include the following: Message Boards; Bookstore; Supplier Directory; and Articles & Case Studies. Recent articles from the site's archives section include: "Kathleen's First Wheelchair" by Adrienne Falk Bergen, PT, ATP/S CRTS, and "Interfacing Assistive Technology with Power Wheelchairs–Part 3" by Michelle L. Lange, OTR, ABDA, ATP.

Web portals: Nearly all the commercial Web portals will have a central "Travel" link that you can explore further for special needs topics. If you are looking for quick results, you can also make use of these site's search engines by typing pertinent keywords such as "travel + disability." Any one of the following portals can be a good starting point for your research on topics pertaining to travel and mobility: Yahoo! (http://www.yahoo.com); AOL (http://www.aol.com); Lycos (http://www.lycos.com); MSN (http://www.msn.com) or AltaVista (http://www.altavista.com). **EP**

E-mail your comments on this article, or other ideas or suggestions for EParent.com, to: Vanessa B. Ira, Internet Projects Advisor and Consultant, at: vira@eparent.com. Or call (201) 634-6550 ext. 213.

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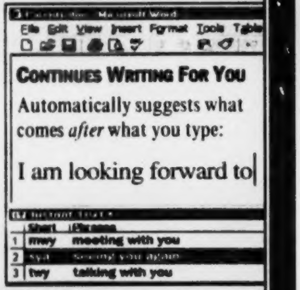

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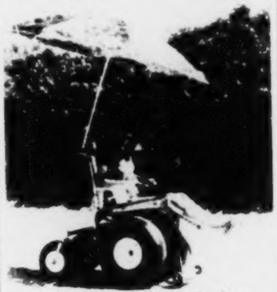

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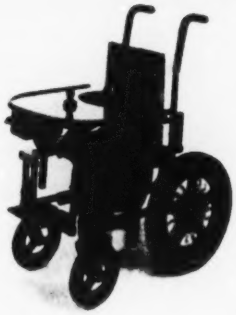

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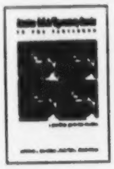

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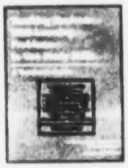

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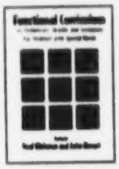

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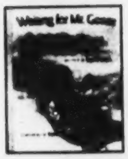

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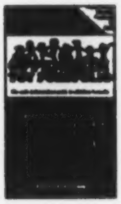

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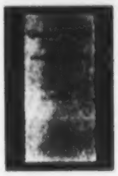

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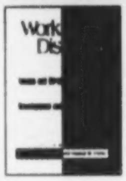

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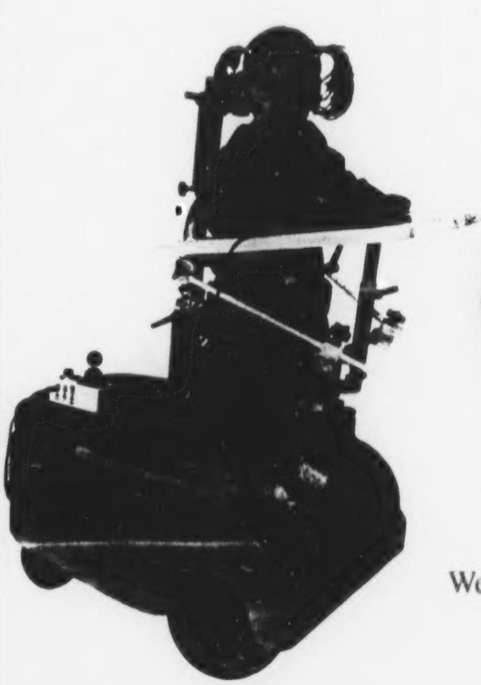

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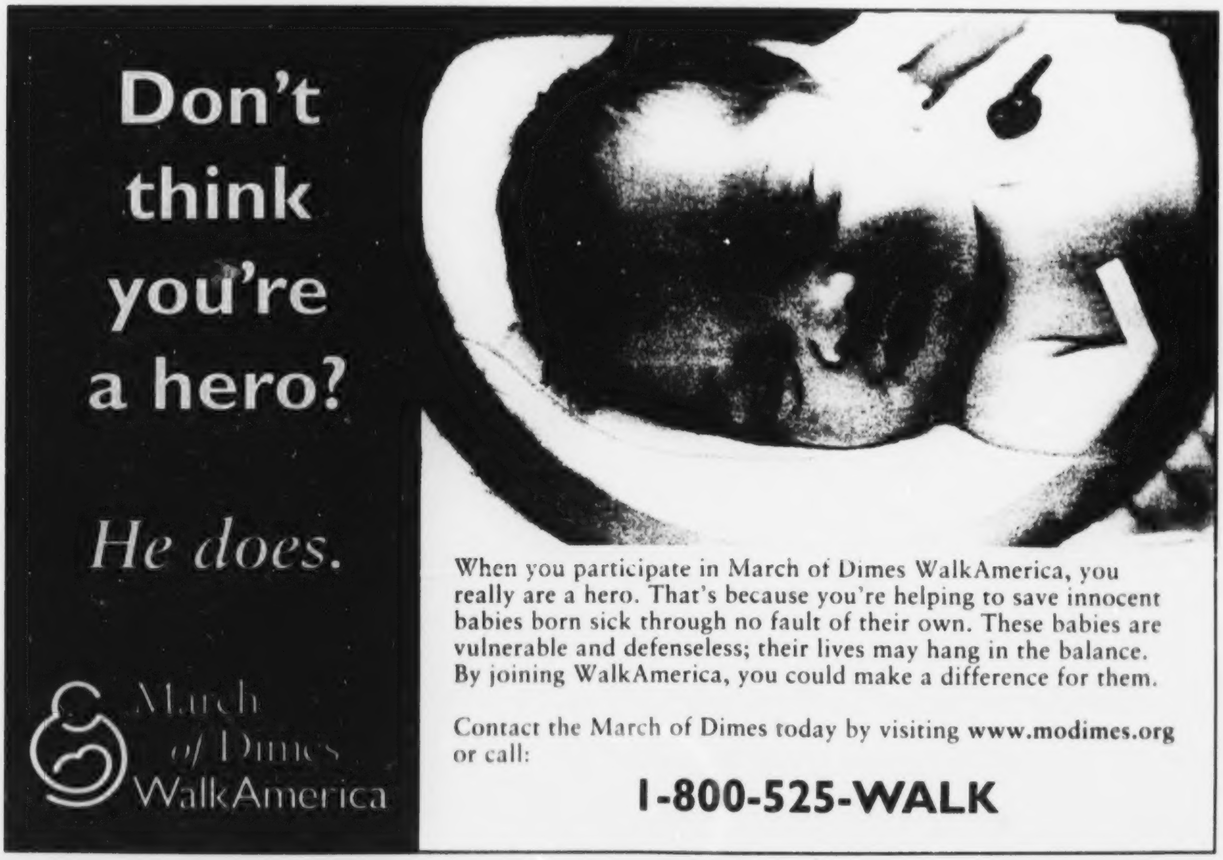
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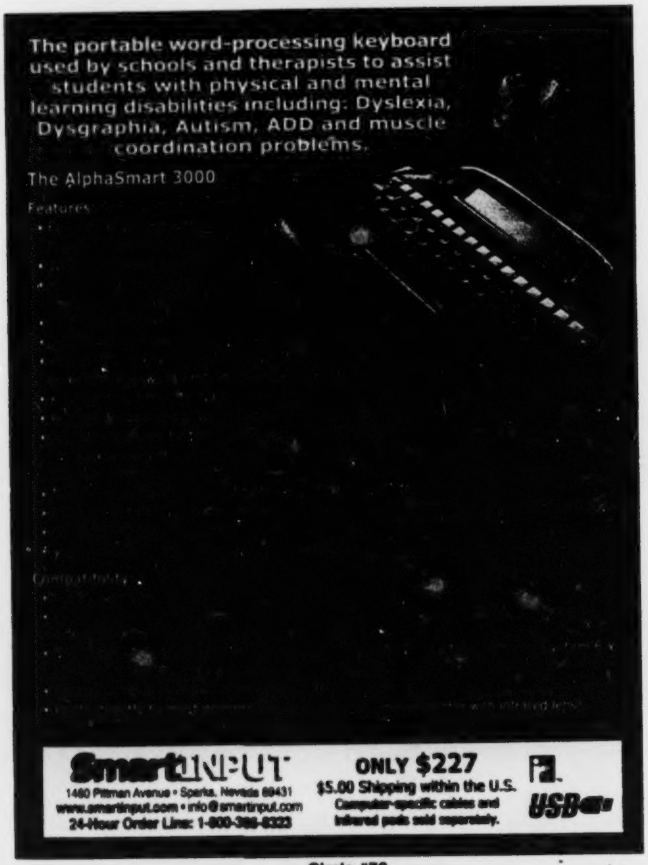
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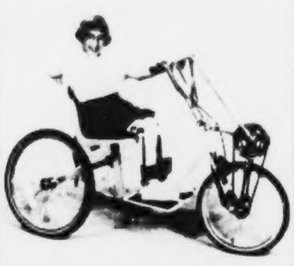

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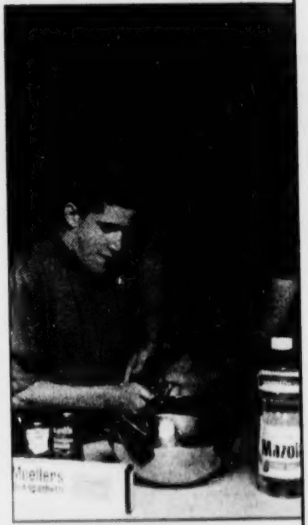

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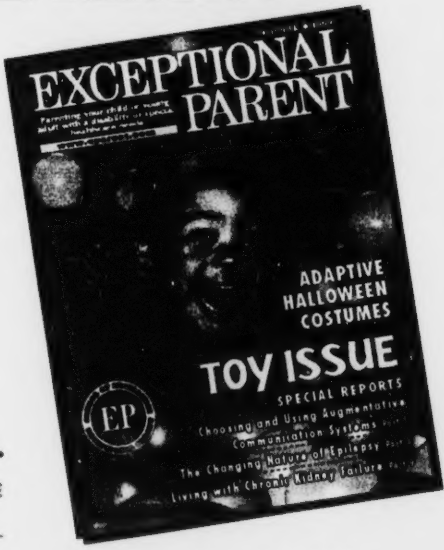
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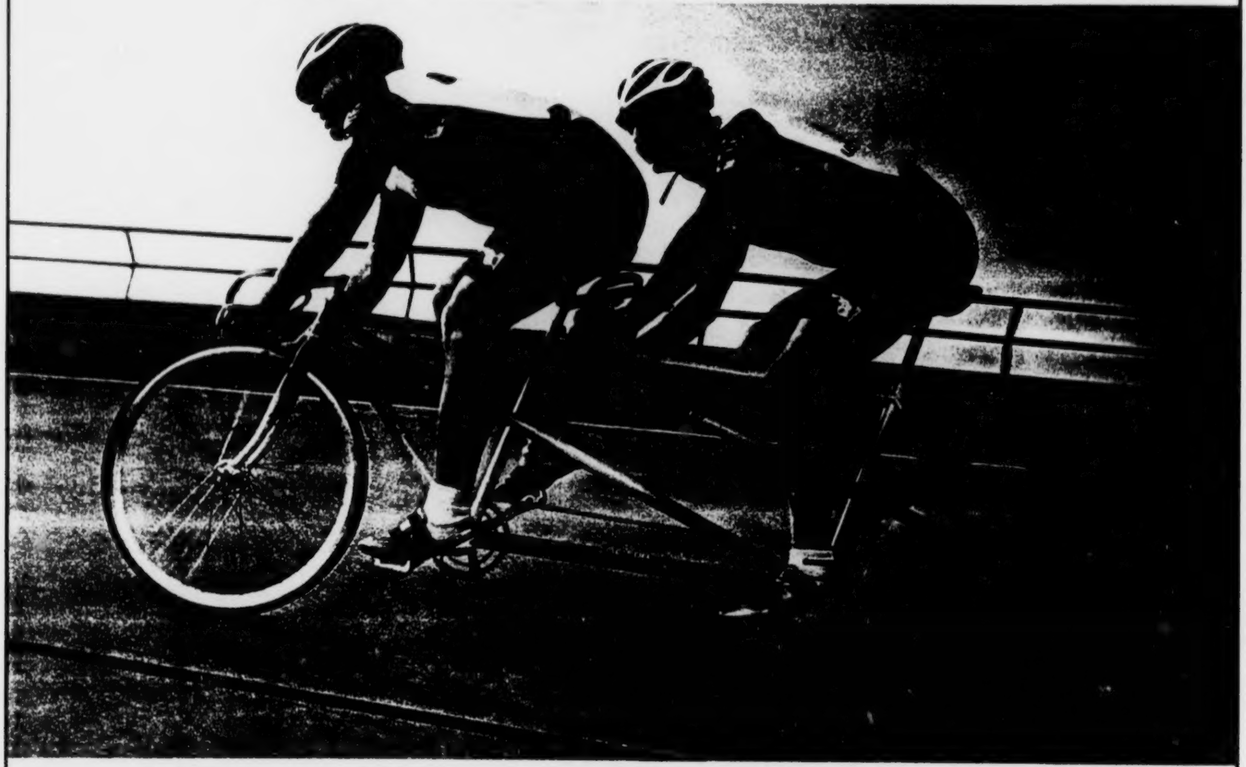

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Will You Hold My Hand?

By Amanda Eckel

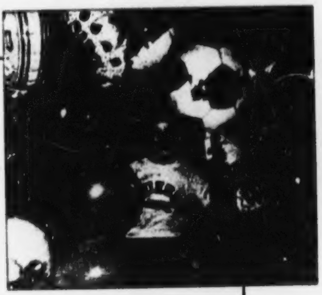
My brother's name is Joc French. He is 6 years old and is in the first grade. Joc is a very bright child. He was diagnosed with mild spastic cerebral palsy (CP) at the age of 1. Each morning he wakes up knowing he has a long day ahead of him, with school and therapy five days a week.

His big brown eyes are always full of hope and you will never hear him complain. Independence is very important to him. If I try to help him with a new task he quickly lets me know that he can do it.

This little trouper has been through many surgeries. His latest one was in January 1999, a dorsal rhizotomy (a procedure performed on the lower portion of the spinal cord to diminish tone in spastic muscles of the lower limbs). I held his hand and gave him my prayers every step of the way. Sometimes I think these things may be harder on the family than on him. He is a strong little guy, full of determination and well-deserved pride.

Joc and I were on our way home the other day, and he asked me a question. He said "Sis, if God loves me so much then why did he give me CP?" With tears in my eyes, I replied, "Sweetie, God loves you so much, and he knew you were a strong little guy, so..." I was speechless. For the first time, I had no answer for him. I do not understand why things happen—nobody does. I do know that my family and I have been blessed with an angel. Joc is the best gift God could ever have given me. He has taught me about dedication as well as determination. Most of all, my brother has shown me what a gift every moment of life is. Thank you, Joc, for being my guide. **EP**

Amanda Eckel and her little brother Joc French.



Joc gets a warm welcome home after his surgery.

The family on Christmas day. Back row, l-r: Mike, Mark (Joc's dad), and Clay. Front row, Amanda, Joc, and Tammy.

Mom's turn

I was looking for something on our computer when I came across a file titled "Will you hold my hand?" When I opened it, I found this paper my daughter Amanda had written about Joc. I was so touched. When I asked Amanda about it, she told me she had gotten a school writing assignment. She chose to write about cerebral palsy and Joc.

We are thankful every day for all of our children. They are all very special. Amanda was 10 years old when Joc was born, and I am sure at times she felt left out when he was getting so much attention. Amanda is now 18 years old and is a very lovely young lady. Joc also has two older brothers, my husband's sons Michael, 24, and Clay, 19. Our whole family has learned a lot since Joc was born. We have learned patience, dedication, and what family unity is all about.

Joc is now 7 years old and attends the second grade. He enjoys playing the piano, horseback riding, swimming, camping, and riding his four-wheeler. He has physical therapy three times a week, and occupational therapy once a week. He is improving all the time.

Amanda lives in Lovington IL, with Joc, her mom, Tammy French, and stepfather, Mark French.

Now on the Web! *We will now be including Familiar Faces and Children's Page on our Web site, www.eparent.com. Please send us your photographs with the understanding that doing so gives Exceptional Parent permission to put the photos on the Exceptional Parent Web site, exactly as they appear in the magazine.*

The Children's Page welcomes contributions from children who have disabilities, their siblings, and their friends. Be creative! **Send your stories, photos and/or artwork** to: **Children's Page,** *Exceptional Parent,* 555 Kinderkamack Road, Oradell, NJ 07649-1517. **Be sure to include your name, address, and day-time telephone number!**

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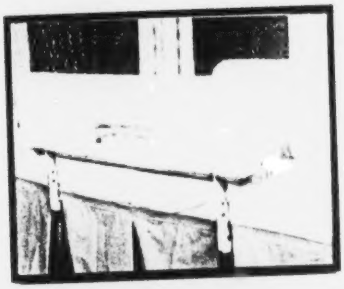

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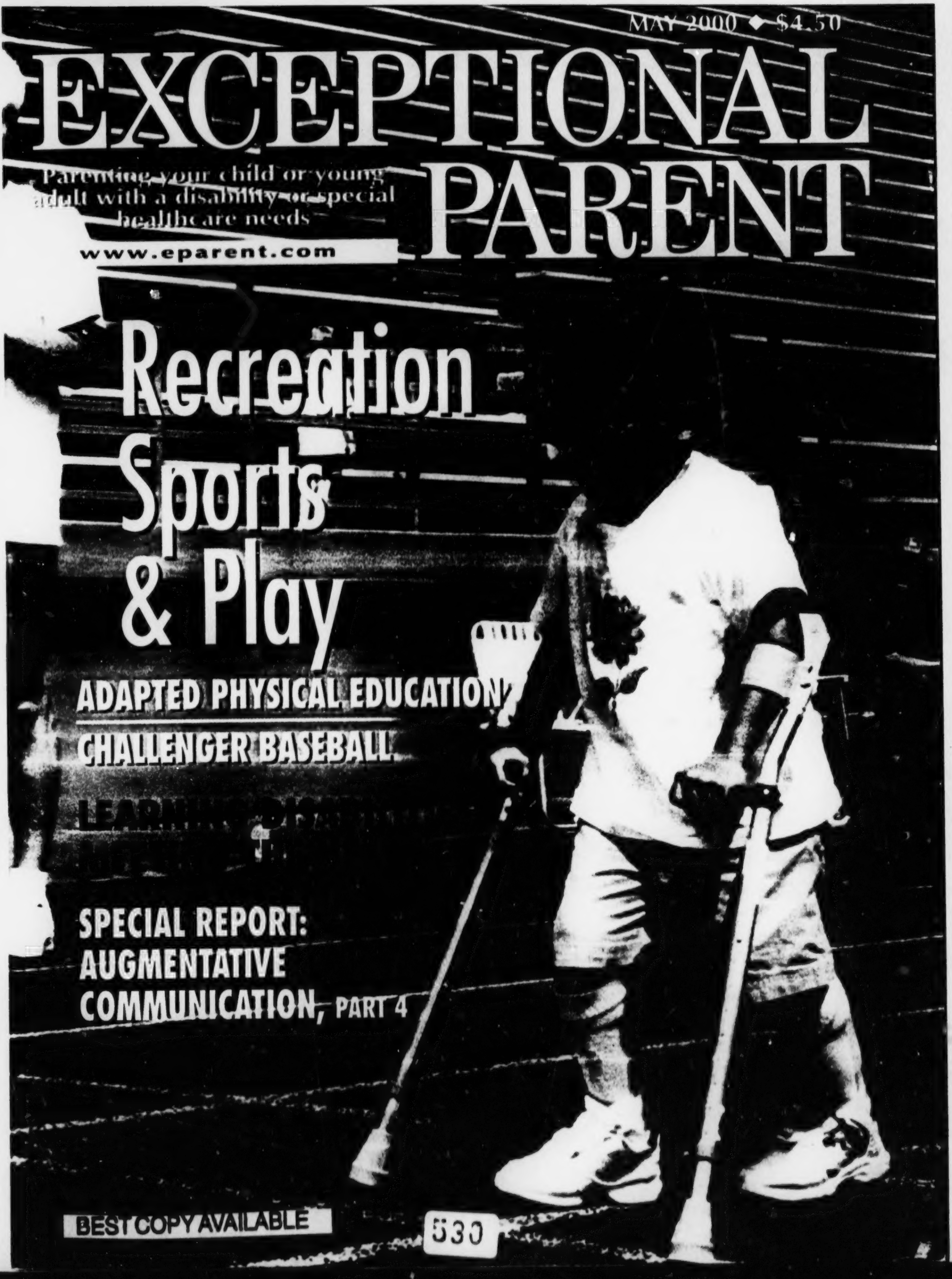

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Adverse events reported with Carnitor use include nausea, vomiting, body odor, gastritis, and seizures. There are no reported contraindications or warnings.

Please refer to the attached brief summary of prescribing information.

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Carnitor®
levocarnitine

Tablets 330mg • Oral Solution 1g/10mL

CARNITOR® (levocarnitine) Tablets (330 mg)
CARNITOR® (levocarnitine) Oral Solution (1 g/10 mL multidose)
FOR ORAL USE ONLY. Not for parenteral use. Rx only.

BRIEF SUMMARY
The following is a brief summary. Please see package insert for full prescribing information.

CLINICAL PHARMACOLOGY
CARNITOR® (levocarnitine) is a naturally occurring substance required in mammalian energy metabolism. It has been shown to facilitate long-chain fatty acid entry into cellular mitochondria, therefore delivering substrate for oxidation and subsequent energy production. Fatty acids are utilized as an energy substrate in all tissues except the brain. In skeletal and cardiac muscle they serve as major fuel. Primary systemic carnitine deficiency is characterized by low plasma, RBC, and/or tissue levels. It has not been possible to determine which symptoms are due to carnitine deficiency and which are due to the underlying organic acidemia, as symptoms of both abnormalities may be expected to improve with carnitine. The literature reports that carnitine can promote the excretion of excess organic or fatty acids in patients with defects in fatty acid metabolism and/or specific organic acidopathies that bioaccumulate acyl CoA esters.

Secondary levocarnitine deficiency can be a consequence of inborn errors of metabolism. CARNITOR® may alleviate the metabolic abnormalities of patients with inborn errors that result in accumulation of toxic organic acids. Conditions for which this effect was demonstrated are: glutaric aciduria II, methyl malonic aciduria, propionic acidemia, and medium chain fatty acyl CoA dehydrogenase deficiency. Autointoxication occurs in these patients due to the accumulations of acyl CoA compounds that disrupt intermediary metabolism. The subsequent hydrolysis of the acyl CoA compound to its free acid results in acidosis that can be life threatening. Levocarnitine clears the acyl CoA compound by formation of acyl carnitine which is quickly excreted.

Levocarnitine deficiency is defined biochemically as abnormally low plasma levels of free carnitine, (less than 20 μmol/L at one week post term) and may be associated with low tissue and/or urine levels. Further, this condition may be associated with a ratio of plasma ester/free levocarnitine levels greater than 0.4 or abnormally elevated levels of esterified levocarnitine in the urine. In premature infants and newborns, secondary deficiency is defined as plasma free levocarnitine levels below age related normal levels.

BIOAVAILABILITY/PHARMACOKINETICS
In a relative bioavailability study in 15 healthy adult male volunteers CARNITOR® Tablets were found to be bio-equivalent to CARNITOR® Oral Solution. Following the administration of 1980 mg b.i.d., the maximum plasma concentration level (C_{max}) was 80 nmol/mL and the time to maximum concentration (T_{max}) occurred at 3.3 hours. There were no significant differences for AUC and urinary excretion observed between these two formulations.

In the same bioavailability study of 15 healthy adult males, CARNITOR® (levocarnitine) Injection administered as a slow 3 minute bolus intravenous injection at a dose of 20 mg/kg showed that free levocarnitine plasma profiles are best fit by a two compartment model. Approximately 76% of free levocarnitine is eliminated in the urine. Using plasma levels uncorrected for endogenous levocarnitine, the mean distribution half life was 0.585 hours and the mean apparent terminal elimination half life was 17.4 hours following a single intravenous dose.

The absolute bioavailability of L-carnitine from CARNITOR® Tablets and Oral Solution was determined compared to the bioavailability of L-carnitine from CARNITOR® Injection Intravenous in 15 healthy male volunteers. After correction for circulating endogenous levels of L-carnitine in the plasma, absolute bioavailability was 15.1% ± 5.3% for L-carnitine from CARNITOR® Tablets and 15.9% ± 4.9% from the Oral Solution.

Total body clearance of L-carnitine (Dose/AUC including endogenous baseline levels) was a mean of 4.00 L/hr. Endogenous baseline levels were not subtracted since total body clearance of L-carnitine does not distinguish between exogenous sources of L-carnitine and endogenously synthesized L-carnitine. Volume of distribution of the intravenously administered dose above baseline endogenous levels was calculated to be a mean of 29.0 L ± 7.1 L (approximately 0.39 L/kg) which is an underestimate of the true volume of distribution since plasma L-carnitine is known to equilibrate slowly with, for instance, muscle L-carnitine.

L-carnitine was not bound to plasma protein or albumin when tested at any concentration or with any species including the human.

INDICATIONS AND USAGE
CARNITOR® (levocarnitine) is indicated in the treatment of primary systemic carnitine deficiency. In the reported cases, the clinical presentation consisted of recurrent episodes of Reye-like encephalopathy, hypoketotic hypoglycemia, and/or cardiomyopathy. Associated symptoms included hypotonia, muscle weakness and failure to thrive. A diagnosis of primary carnitine deficiency requires that serum, red cell and/or tissue carnitine levels be low and that the patient does not have a primary defect in fatty acid or organic acid oxidation (see Clinical Pharmacology). In some patients, particularly those presenting with cardiomyopathy, carnitine supplementation rapidly alleviated signs and symptoms. Treatment should include, in addition to carnitine, supportive and other therapy as indicated by the condition of the patient.

CARNITOR® (levocarnitine) is also indicated for acute and chronic treatment of patients with an inborn error of metabolism that results in a secondary carnitine deficiency.

CONTRAINDICATIONS
None known.

WARNINGS
None.

PRECAUTIONS
General
CARNITOR® (levocarnitine) Oral Solution is for oral/internal use only.
Not for parenteral use.
Gastrointestinal reactions may result from too rapid consumption of carnitine. CARNITOR® (levocarnitine) Oral Solution may be consumed alone, or dissolved in drinks or other liquid foods to reduce taste fatigue. It should be consumed slowly and doses should be spaced evenly throughout the day to maximize tolerance.

Carcinogenesis, mutagenesis, impairment of fertility
Mutagenicity tests performed in *Salmonella typhimurium*, *Saccharomyces cerevisiae*, and *Schizosaccharomyces pombe* indicate that CARNITOR® (levocarnitine) is not mutagenic. Long-term animal studies have not been conducted to evaluate the carcinogenicity of the compound.

PREGNANCY
Pregnancy Category B.
Reproductive studies have been performed in rats and rabbits at doses up to 3.8 times the human dose on the basis of surface area and have revealed no evidence of impaired fertility or harm to the fetus due to CARNITOR®. There are, however, no adequate and well controlled studies in pregnant women. Because animal reproduction studies are not always predictive of human response, this drug should be used during pregnancy only if clearly needed.

NURSING MOTHERS
It is not known whether this drug is excreted in human milk. Because many drugs are excreted in human milk, a decision should be made whether to discontinue nursing or to discontinue the drug, taking into account the importance of the drug to the mother.

PEDIATRIC USE
See Dosage and Administration.

ADVERSE REACTIONS
Various mild gastrointestinal complaints have been reported during the long-term administration of oral L- or D,L-carnitine; these include transient nausea and vomiting, abdominal cramps, and diarrhea. Mild myasthenia has been described only in uremic patients receiving D,L-carnitine. Gastrointestinal adverse reactions with CARNITOR® (levocarnitine) Oral Solution dissolved in liquids might be avoided by a slow consumption of the solution or by a greater dilution. Decreasing the dosage often diminishes or eliminates drug-related patient body odor or gastrointestinal symptoms when present. Tolerance should be monitored very closely during the first week of administration, and after any dosage increases.

Seizures have been reported to occur in patients with or without pre-existing seizure activity receiving either oral or intravenous levocarnitine. In patients with pre-existing seizure activity, an increase in seizure frequency and/or severity has been reported.

OVERDOSAGE
There have been no reports of toxicity from carnitine overdosage. The oral LD_{50} of levocarnitine in mice is 19.2 g/kg. Carnitine may cause diarrhea. Overdosage should be treated with supportive care.

DOSAGE AND ADMINISTRATION
CARNITOR® (levocarnitine) Tablets.

Adults: The recommended oral dosage for adults is 990 mg two or three times a day using the 330 mg tablets, depending on clinical response.

Infants and children: The recommended oral dosage for infants and children is between 50 and 100 mg/kg/day in divided doses, with a maximum of 3 g/day. Dosage should begin at 50 mg/kg/day. The exact dosage will depend on clinical response.

Monitoring should include periodic blood chemistries, vital signs, plasma carnitine concentrations and overall clinical condition.

CARNITOR® (levocarnitine) Oral Solution.
For oral use only. **Not for parenteral use.**

Adults: The recommended dosage of levocarnitine is 1 to 3 g/day for a 50 kg subject, which is equivalent to 10 to 30 mL/day of CARNITOR® (levocarnitine) Oral Solution. Higher doses should be administered only with caution and only where clinical and biochemical considerations make it seem likely that higher doses will be of benefit. Dosage should start at 1 g/day, (10 mL/day), and be increased slowly while assessing tolerance and therapeutic response. Monitoring should include periodic blood chemistries, vital signs, plasma carnitine concentrations, and overall clinical condition.

Infants and children: The recommended dosage of levocarnitine is 50 to 100 mg/kg/day which is equivalent to 0.5 mL/kg/day CARNITOR® (levocarnitine) Oral Solution. Higher doses should be administered only with caution and only where clinical and biochemical considerations make it seem likely that higher doses will be of benefit. Dosage should start at 50 mg/kg/day, and be increased slowly to a maximum of 3 g/day (30 mL/day) while assessing tolerance and therapeutic response. Monitoring should include periodic blood chemistries, vital signs, plasma carnitine concentrations, and overall clinical condition.

CARNITOR® (levocarnitine) Oral Solution may be consumed alone or dissolved in drink or other liquid food. Doses should be spaced evenly throughout the day (every three or four hours) preferably during or following meals and should be consumed slowly in order to maximize tolerance.

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Cover: Kristen Coles, (shown here at age 6), who has diplegic cerebral palsy, completes her first race ever. A member of the Bennett Blazers from Baltimore, MD, Kristen is crossing the finish line at last year's United States Cerebral Palsy Athletic Association Junior Nationals. In accordance with their philosophy, "equal opportunity for all," USCPAA provides both individualized sports training and competitive opportunities for athletes with CP, or other related challenges. Photo courtesy of USCPAA.

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Parenting your child or young adult with a disability or special healthcare needs

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For subscription and advertising information, see page 75

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EDITOR'S DESK

Swing Into Spring

It is appropriate that our May issue is dedicated to sports, recreation, and play since spring is the time of new growth and the longer days inspire all kinds of activity. Participation in recreational activities is important for the growth and development of all children. They provide opportunities to be included, make new friends, and learn the social skills needed to be part of a group, such as taking turns and playing by the rules. Through recreational activities, children can also learn about themselves and their bodies, laying a foundation for life-long fitness.

School provides a place where recreational skills are learned. Physical education is meant to address current and lifetime fitness needs of a child, and also acts to promote educational and social development. IDEA (the Individuals with Disabilities Education Act) has long required that a physical education assessment be part of the IEP (Individualized Education Plan), and if necessary, that an adapted physical education (adapted PE) program be provided. Generally, parents do not know what to expect from this assessment. Under the heading "Let's Get Physical," we present three articles discussing the aspects of adapted PE: Rebecca Lytle discusses some easy-to-duplicate adapted PE activities, as well as what an adapted PE program is and how to advocate for it; Michael Aitken, who teaches adapted PE on the high school level, describes how adolescents with disabilities can reap social and self-esteem benefits; John Passarini, a teacher of adapted PE, shares with EP's Gale Jurasek his successful methods for inclusion, he also outlines an IEP for adapted physical education.

John was recently honored as the Adapted Physical Education National Teacher of the Year by the American Association for Active Lifestyles and Fitness/Adapted Physical Activity Council for his pioneering efforts in providing access to participation in everyday recreation and games for all children. We are pleased to recognize him this month as an "Exceptional Professional." His innovative techniques to integrate all children into creative games and activities in the school setting and beyond have served to benefit all his students in a multitude of ways.

To set a foundation for life-long physical fitness, the role of the family in teaching the skills necessary for play and recreation is critical. Parents are often unsure how to include the child with a disability. "Wet 'n Wild" by Ryan Mayo of the National Sports Center for the Disabled this month offers rafting as one solution. In addition, Special Olympics International has provided stretching and relaxation exercises that are useful alone or as the first step in preparing for organized sports. In the coming months, we will continue to present more exercises and activities from Special Olympics that can be done at home or at school.

Mark your calendar

Plan to join us May 28-31, 2000 for Humanizing Health Care for Children and Families: The Art of the Relationship, a conference and exhibit hosted by the MassGeneral Hospital for Children in collaboration with EP. Among the topics to be discussed are: family centered care, community/school integration, spiritual care and emotional support. For more information on the event which will take place in Boston, contact Mary Lou Kelleher at MassGeneral at (617) 724-5720.

This November 10-12, EP will co-sponsor The World Congress & Exposition on Disabilities (WCD) in Atlanta, Georgia. We invite individuals with disabilities, families and professionals to take advantage of this opportunity to come together to share their knowledge and experience. For more information, contact the WCD at (877) 923-3976, or (201) 226-1446; Web site: http://www.wcdexpo.com.

Spring is also the time when we turn our attention to the national pastime: baseball. The Challenger League was developed to give youngsters with special needs a "league of their own." Kerry Pianoforte describes the Oradell, New Jersey, Challenger League and how to start a program in your town.

Peggi McNairn and Cindy Schioleno end their excellent series on augmentative and alternative communication, "Can We Talk?" In this concluding installment, individuals who are successful users of AAC devices share their thoughts so that parents, professionals, and other AAC users can learn from their experiences.

EP employee honored

We are proud to announce that one of our staff members here at EP has received a prestigious award. Dennis Dusevic has been recognized for outstanding success in employment by the New Jersey chapter of APSE (Association of Persons in Supported Employment), a national organization dedicated to fostering employment opportunities for people with disabilities. As a co-worker and employee, he has set a great example. Congratulations, Dennis!

Welcome

We are proud to welcome two new members to our Editorial Advisory Board: Lawrence T. Taft, MD, is a professor of pediatrics at the University of Medicine and Dentistry of New Jersey, Robert Wood Johnson Medical School. He has also served as editor-in-chief for our special report, "Positive Perspectives for Cerebral Palsy."

Chris Feudtner, MD, PhD, is a pediatrician at the Pediatric Care Center of the University of Washington, Seattle, and is currently a Robert Wood Johnson Clinical Scholar. A past contributor to our Ask the Doctor column, Dr. Feudtner currently reviews EP's Search and Respond column.

Cast your vote!

Remember to send in your nomination for our Models of Excellence in Education. We are interested in both inclusive and specialized educational programs, pre-school through high school, that have helped young people with disabilities succeed in learning. Send your nominations to:

Education Awards, Exceptional Parent Magazine, 555 Kinderkamack Rd., Oradell, NJ 07649-1517.

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- *To reach out to mothers and fathers of children and young adults who have disabilities and special healthcare needs.*
- *To empower parents and professionals by providing practical information and emotional support.*
- *To appreciate that parents are the most important experts in the lives of their children.*
- *To energize parents and professionals.*
- *To share ideas and experiences so parents, professionals, people who have disabilities, and other advocates can learn from one another and better collaborate to serve all children and families.*

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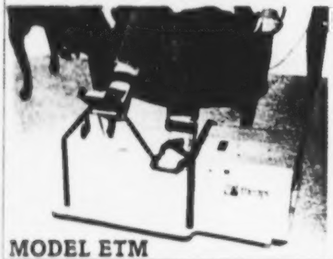

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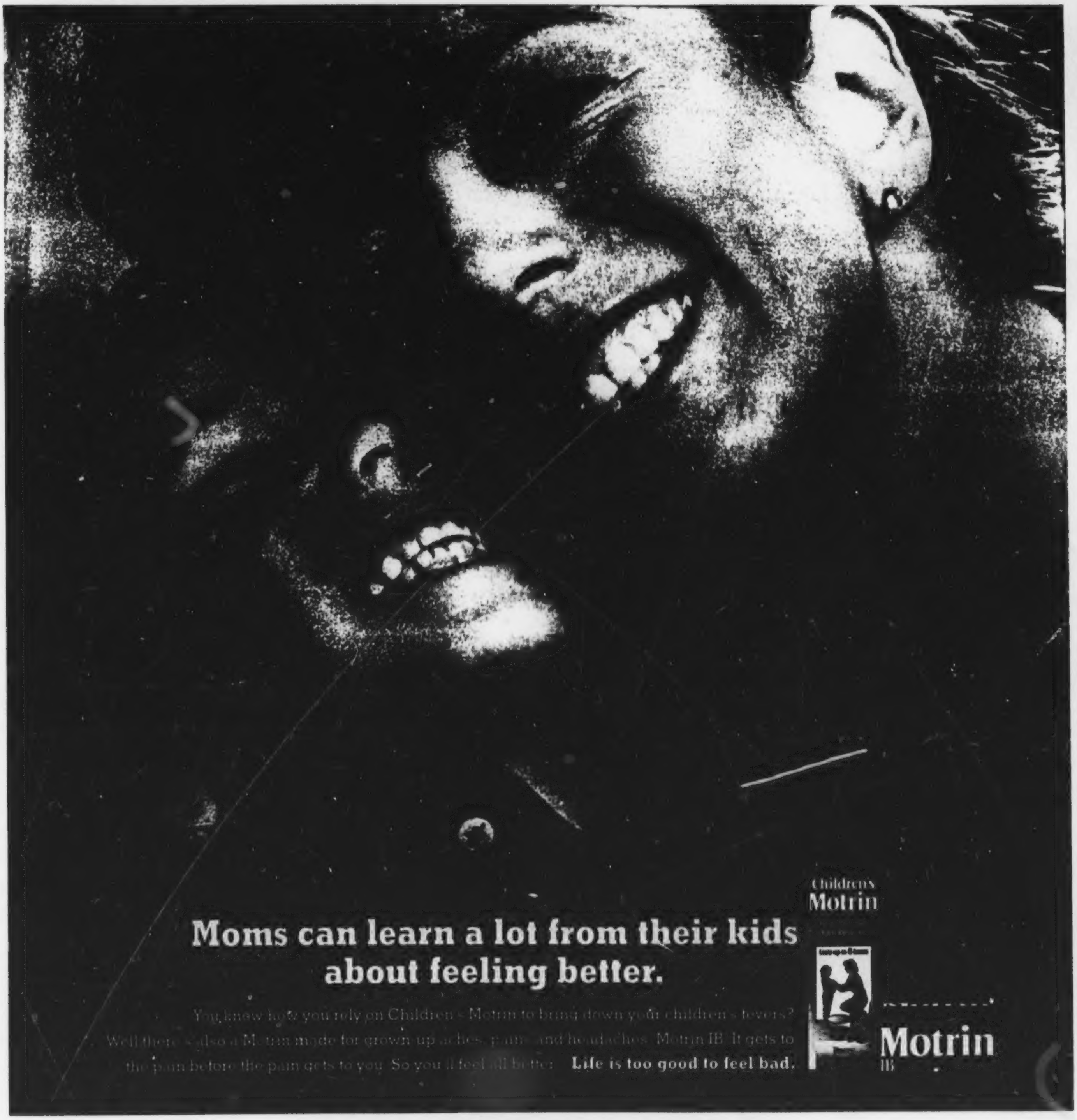

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Search & Respond

Search and Respond is an opportunity for our readers to exchange information about their practical experiences in meeting the everyday challenges of life with a child or adolescent who has a disability. In this column, "S" represents Search letters and "R" represents Respond letters received to a previously printed Search. "Instant S&R" is a new feature which represents e-correspondence we have downloaded from our Web site. All Responds are forwarded to the writers of the original Searches; some are published. Published letters may be edited for purposes of space and clarity. We also expect parents to consult appropriate professionals.

When sending correspondence, please indicate whether it is a Search or a Respond. For Responds, be sure to note in which issue the original Search letter appeared. Please remember to include a phone number on all correspondence, in the event that more information is required. Write to: Exceptional Parent, Attn: Search/Respond, 555 Kinderkamack Rd., Oradell, NJ 07649-1517; Fax to: (201) 634-6570; E-mail to epedit@aol.com; or visit Search and Respond on our Web Site: http://www.eparent.com.

For information about specific disabilities, contact: the National Organization for Rare Disorders (NORD), 100 Rt. 37, PO Box 8923, New Fairfield, CT 06812; (800) 999-6673; (203) 746-6518; Web site: http://www.rarediseases.org. Also, see the "National Resources for Specific Disabilities" directory in Exceptional Parent's 2000 Resource Guide (January 2000, starting page 30).

Each month, Chris Feudtner, MD, PhD, reviews Search & Respond for accuracy and completeness. Dr. Feudtner is a pediatrician at the Pediatric Care Center of the University of Washington in Seattle, and is currently a Robert Wood Johnson Clinical Scholar. Look for Dr. Feudtner's comments on certain Search & Respond letters.

Behavior modification

S I am the proud parent of an 18-year-old son. He has cerebral palsy, epilepsy, is mentally delayed and nonverbal. He uses a wheelchair and also can walk with a walker about 150 feet at a time, does two miles on his tricycle, walks laps in a swimming pool, and walks the bases in Challenger baseball.

He tries hard in everything he does, but he gets bored easily and hits and swats at people when anxious or startled. This hitting is not meant in anger, but is more playful than anything else. However, because of his size, it has become a problem, as this behavior limits his opportunities for growth and friendship.

He has been on Ritalin® and clonidine, which have not worked well enough. It has now been suggested that some adverse-behavioral modification therapy be tried—using electrical stimulation to shock him mildly every time he hits. This would involve attaching a device to his body where he cannot reach it, and using a remote control to administer a shock whenever he hits. He would also have to be put in a "home" while his caregivers learn to use the device.

This seems potentially cruel, so I would like to know if anyone has any experience with this type of treatment.

S.B., Worth, IL

Lamictal for seizures

S I am the mother of two wonderful boys. The elder, who is 5, was diagnosed with spastic quadriplegic cerebral palsy. When he was one and a half, he started having severe seizures and has had them ever since. In November of 1999, he got very sick. We found out that he had pancreatitis from the seizure medication he was taking (valproic acid). Now he is taking Lamictal® (another antiepileptic drug). I would like to hear from anyone else who has experience with Lamictal.

C.B., via the EP Web site

Teenager with Pallister-Killian syndrome

S My daughter is 13-years old and has Pallister-Killian syndrome. I am looking for someone with a teenage daughter who can tell me what to expect with the onset of puberty. My daughter has profound mental retardation and cannot tell me when anything is bothering her. She also has seizures at night, which started a year ago. Even with medication (Lamictal), the seizures are not under control yet.

Glenda, via the EP Web site

EDITOR'S NOTE:
The Pallister-Killian Family Support Network can be reached at:
3700 Wyndale Ct.
Fort Worth, TX 76109
Phone: (817) 927-8854
Fax: (817) 927-2073

Pediatric dentist

S My 20-year-old son, who has mental retardation, has a dental cavity for the first time in his life. The pediatric dentist, who was wonderful with him, retired a few months ago. The dentist who took over the practice is unable to even clean my son's teeth, let alone think about filling a cavity. He has proposed setting him up for intravenous anesthesia just so he can fill the cavity, even though he has never done this before. My son is taking Depakote® for minor seizures, but the dentist has assured me that the anesthesia should not be a problem. He also said that since the anesthesia should take effect within a minute, it should not be a problem to keep the needle in his arm for that period of time. I would like to know how other parents have dealt with dental care for their children, especially in a case like this where drilling has to be done

G.J., via the EP Web site

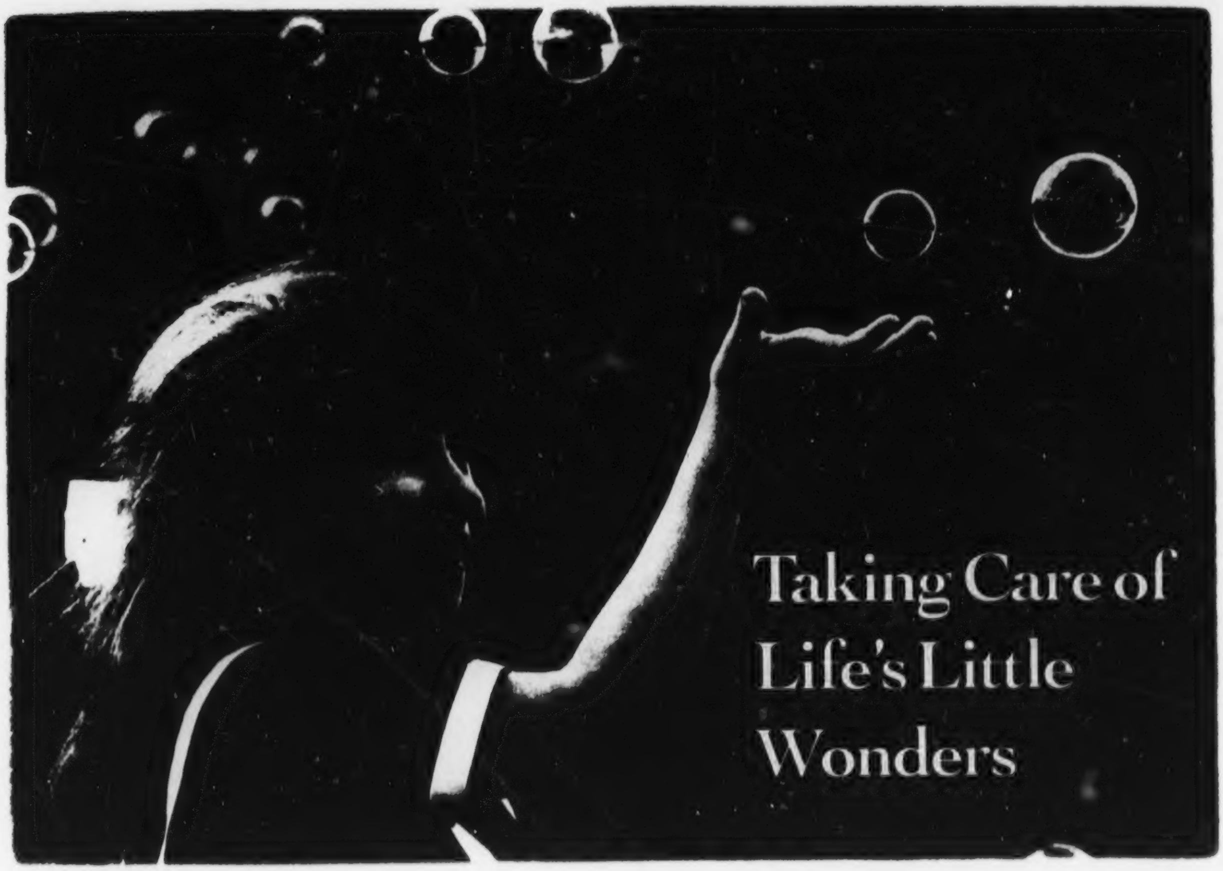
Dr. Feudtner: *Call the nearest children's hospital, speak to their dental department, and see if they can recommend a nearby dentist who deals with children/young adults with special needs.*

Respite

R *Marcy, February 2000 (via the EP Web site), lives in Michigan and is the mother of two children with severe disabilities. Marcy cannot get respite or nursing help because the family income is too high.*

If you live in Wayne County, contact

continued on page 14



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Search & Respond

continued from page 12

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Kristen Cope, VPA, Parent Support
and Advocacy Program (PSAP)
Phone: (734) 266-9300

Swing needed

R *M.V. March 2000 (via the EP Web site), is looking for a swing for her 8-year-old son who has Angelman's syndrome and has outgrown his toddler swing.*

I recently obtained a yard swing from Brookstone Store that can be used on a frame or hung like a porch swing. It is a filled canvas, so it is soft and sling-like. They come for one or two people. We hang ours indoors for the winter and outside in warm weather. It is comfortable and fun for us to use with our son who has multiple disabilities. The price is about $300-400, but it was worth it because our son has gotten a lot of enjoyment from it.

P.B., via the EP Web site

The Rehabilitation Centre for Children in Winnipeg, Manitoba, Canada, custom-makes swings for children with disabilities. The frame is chromed steel, the upholstery is canvas, and suspension is via four lengths of chain that can be adjusted to position the swing at the desired angle of recline.

The necessary measurements are: seat to top of head, seat to armpit, seat to bend of knee, hip width, and chest width. The swing can be adjusted for an exact fit. The current price of this swing is $350 Canadian. For further information, contact:

Rehabilitation Centre for Children
633 Wellington Crescent
Winnipeg, Manitoba
Canada R2M 0A8
Phone: (204) 452-4311
Fax: (204) 477-5547

EDITOR'S NOTE:
Other suggestions for locating a swing include the "Abilitations-Spring 2000" catalog. The phone number for catalog orders is (800) 850-8602. The company's Web address is http://www.abilitations.com.

Instant S&R

Sign language

S I am the parent of a 6-year-old girl who is undiagnosed. She has microcephaly, mild mental retardation, and developmental delays in all areas. Her hearing is fine, but she is unable to speak. She uses sign language as her mode of expressive communication. Her vocabulary in sign is currently at about 650 signs. We are interested in hearing from other parents who have children who use sign language. We would also like to know how many individuals with disabilities, other than hearing impairments, use sign language for their primary means of communication.

J.M., via the EP Web site

R My son, who is 2, was born with hydrocephalus, agenesis of the corpus callosum (a rare disorder in which the two hemispheres of the brain are not connected), an arachnoid cyst, and cerebral palsy. We started teaching him sign language about a year ago. He is very delayed in his oral motor skills. We started speech therapy a year ago, and it has not helped. I am so happy we started signing. He is up to 30 words, and he can communicate with us. I am constantly asked in public if my son is deaf and why he is deaf. I have to explain that his hearing is fine, he just cannot speak. Sign language has been a blessing to us because my son has a hard enough time without having to deal with the total frustration of not being able to speak. One of the first signs we taught him was "hurt." He has since been able to tell us where he hurts and when.

Maria, via the EP Web site

Twins—one with cerebral palsy, one without

S We have 15-month-old twin sons. One has cerebral palsy, the other does not. I would like to hear from a parent in a similar situation.

Anonymous, via the EP Web site

R I also have twin sons; mine are 18 months old. One of them has moderate diplegic cerebral palsy, and the other is "normal" by all accounts. My son with the disability is a beautiful boy with a sweet temperament, but sometimes I see the frustration in his eyes when he is left behind. It is hard to know when to help and when not to help him, so that he can work it out and gain confidence. We are involved in an early intervention program through our city's school district and the occupational and speech therapy are helpful, but they do not take all the pain away. I work hard trying to ensure that both my sons know how much they are individually loved and that the CP does not get in the way of either one's emotional development. I think that, in the long run, they will help and learn from one another. My love for both of them grows by the day.

M.T., via the EP Web site

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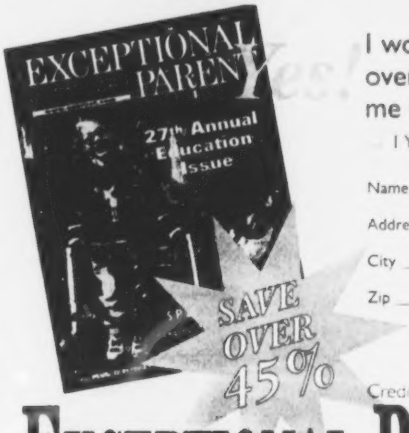

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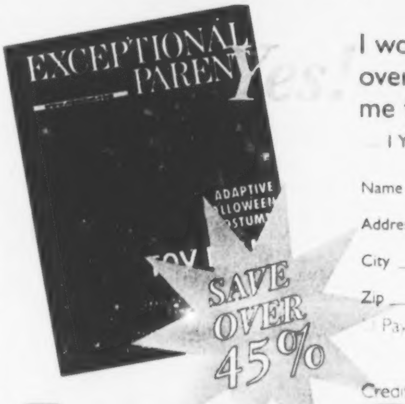

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Exceptional Parent

is the magazine for parents and professionals involved in the care and development of children and young adults with special needs, including Physical Disabilities, Developmental Disabilities, Mental Retardation, Autism, Epilepsy, Learning Disabilities, Perceptual Disabilities, Hearing Impairments, Vision Impairments, Emotional Problems, Chronic Illness.

Exceptional Parent's MISSION IS TO:

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practical guidance and support for parents, educators and professionals;

INFORM
parents and professionals about current and changing rights, laws and programs for children and young adults with disabilities, and their families;

SERVE
as a network, a forum for the exchange of ideas, experience and advice between parents, professionals and educators;

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President

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Circle #51

WHAT'S HAPPENING

Sesame Street launches literacy program

Sesame Street Beginnings is a new literacy program which aims to increase awareness of the important role parents and caregivers play in young children's language development. Available in both English and Spanish, the Sesame Street Beginnings kit includes a 25-minute videotape, 15-minute audiocassette, and package of printed material. The video combines scenes shot on the Sesame Street set and live-action footage of positive interaction between parents and children. The cassette features songs that parents and children can sing along to. The printed materials include a poster; bookplates; a "Parent Pages" booklet outlining the major messages and offering easy activities; and a Facilitator Guide geared to professionals working with parents, early childhood educators, and literacy providers.

Sesame Street Beginnings will be distributed free of charge to childcare programs, local childcare resource and referral agencies, family literacy programs, and public health and community-based organizations. Additional kits will be available at cost by writing to Children's Television Workshop, Health and Safety Outreach, PO Box 55742, Indianapolis, IN 46205-0742. Information will also be on their Web site: http://www.sesamestreet.com.

continued on page 22

CALENDAR OF EVENTS

JUNE 2-3

The 2000 International Conference on Mitochondrial Diseases "Mitochondrial Cytopathies 2000"

CLEVELAND MARRIOTT HOTEL, CLEVELAND, OH

Topics will include families dealing with chronic illness, nutritional support, genetics, and treatment.

For more information contact United Mitochondrial Disease Foundation: Phone: (412) 793-8077; Fax: (412) 793-8077; or Web site: http://biochemgen.ucsd.edu/umdf.

JUNE 4-8

Early Connections: Developing Partnerships in Services to Young Children with Visual Impairments (birth to age 8)

UNIVERSITY OF BRITISH COLUMBIA, VANCOUVER, BRITISH COLUMBIA, CANADA

This conference will focus on the needs and rights of young children with visual impairments, including those who have multiple disabilities and deafblindness. For more information contact Early Connections Secretariat, UBC Conference Centre, 5961 Student Union Boulevard, Vancouver, BC, Canada V6T 2C9; Phone: (604) 822-1050; Fax: (604) 822-1069; E-mail: registration@housing.ubc.ca.

JUNE 9-13

Training Institutes Developing Local Systems of Care for Children and Adolescents with Emotional Disturbances and their Families: Improving Policy and Practice

SHERATON NEW ORLEANS HOTEL, NEW ORLEANS, LA

This conference is open to both mental health professionals and parents. Topics will include managed care, early childhood mental health, and family involvement and family-professional partnerships. For more information, contact the National Technical Assistance Center for Children's Mental Health, Georgetown University Child Development Center; Phone: (202) 687-5000; Fax: (202) 687-19544.

JUNE 24

Cornelia de Lange Syndrome Connections Meeting: Focus on Communication

DOUBLE TREE HOTEL, SCOTTSDALE, AZ

The main session is entitled "Communication at its Best." Other topics will include "Making Connections," and "Building Communities."

For more information contact the Cornelia de Lang Foundation; Phone: (800) 753-2357; E-mail: families@cdlsus.org; Web site: http://www.cdlsoutreach.org/news/features.htm.

JUNE 23-25

7th International Conference on Lowe Syndrome

RENAISSANCE WAVERLY HOTEL ATLANTA, GA

This conference will feature presentations by leading experts on medical care, the latest research, growth hormone therapy, behavior management, and family and educational issues.

For information contact Lowe Syndrome Association, 222 Lincoln St., West Lafayette, IN 47906; Phone: (765) 743-3634; Web site: http://www. lowesyndrome.org; or E-mail: info@ lowesyndrome.org.

JUNE 28-30

Spina Bifida Association of America 2000 Annual Conference

FOUR POINT SHERATON, MILWAUKEE, WI

Topics will include the mediation process, physical fitness for the physically challenged, and update on fetal surgery 2000. Phone: (202) 944-3285; Fax: (202) 944-3295; E-mail: sbaa@sbaa.org; Web site: http://www.sbaa.org.

JUNE 28-JULY 2

Resna 2000 Annual Conference Technology for the New Millennium

Omni Rosen Hotel, Orlando, FL

This assistive technology event is for providers and consumers of technology devices and services. Topics will include applying universal design principles to assistive technology devices, peer coaching for AT users, electronic aids to daily living, and much more. For more information contact Resna at Phone: (793) 524-6686; TTY: (703) 524-6639; Fax: (793) 524-6630; E-mail: sleone@resna.org; or Web site: http://www.resna.org.

Sports and Exercise for Children with Chronic Health Conditions

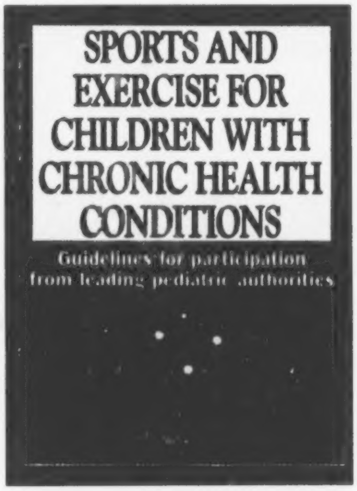
EDITED BY BARRY GOLDBERG, MD

1995; Human Kinetics Publishers, Inc.: 381 pages
Available through the EP Library: (800) 535-1910; code HK101GN
Cost: $52.00 plus shipping and handling

In the preface to *Sports and Exercise for Children with Chronic Health Conditions*, Dr. Goldberg writes that this book "is the first-ever comprehensive set of guidelines for how children with chronic health conditions can participate in sports and exercise."

The book is divided into two sections: one on general issues which comprises four chapters and one which addresses specific chronic conditions.

In the first chapter, "Impact of Chronic Health Conditions in Childhood," the authors, Nancy E. Lanphear, MD, Gregory S. Liptak, MD, and Michael Weitzman, MD, discuss their belief that all children with chronic health conditions have the ability to participate in sports. They give a list of questions to be used by professionals and families to help make decisions regarding a child's participation in sports.


SPORTS AND EXERCISE FOR CHILDREN WITH CHRONIC HEALTH CONDITIONS
Guidelines for participation from leading pediatric authorities

"The Benefits and Risks of Sports and Exercise for Children With Chronic Health Conditions," by Michael A. Nelson, MD, and Sally S. Harris, MD, MPH, is the second chapter. Physical and psychosocial benefits of exercise, as well as risks associated with exercise are examined. Below are excerpts from different sections of the chapter.

On benefits of exercise in general the author writes, *"Some components of physical fitness include balance, coordination, speed, and power. Improvement in these factors can contribute to motor development, skill mastery, feelings of competence and achievement, and athletic success for all children. Health-related components of physical fitness include cardiopulmonary endurance, body composition, muscle strength and endurance, and flexibility. Improvement in these areas is associated with reductions in risk factors associated with various disease states."*

Going beyond the physical, the author also examines some of the by-products of exercise: *"Exercise programs provide children with chronic diseases the same opportunity for enjoyment and social interaction as healthy children, and may promote feelings of normality. Apart from any specific effects of exercise on mental health, exercise programs simply help children to feel good about themselves; exercise and participation in sport often produces a general sense of well-being."*

Addressing concerns about risks of exercise the author points out: *"The most common contributing factor potentially associated with all chronic diseases is a rapid change from a sedentary lifestyle to one of intense physical activity. Avoiding overuse injuries will require a very gradual increase in physical activity for many of these youngsters if they are to include regular exercise programs in their lives."*

The book's third chapter, "Considerations for Sports Selection and Preparatory Training," by Dr. Goldberg, Arthur M. Pappas, MD, and Nancy M. Cummings, MD, covers recommendations for activities and assessment of baseline physical activity and fitness. There are tables classifying sports according to contact potential, aerobic intensity, static and dynamic demands (i.e., muscle groups used, demand placed on the heart, which sports raise blood pressure), and motion ratings.

The final chapter in Section I, "Legal Issues Regarding Children With Chronic Health Conditions," by Leonard Rieser, JD, and Sarah D. Cohn, JD, discusses the legal rights of children with chronic health conditions to participate in sports. They review the ADA and IDEA definitions of eligibility, and tell families what procedures to follow to establish their child's eligibility rights under these statutes.

Part II of the book, "Sports, Exercise, and Specific Chronic Health Conditions," is a series of 20 chapters, each devoted to a specific condition; the effects of exercise on the condition; exercise and sports programs that are appropriate; preparation; and instructions for healthcare personnel, where applicable.

Sports and Exercise for Children with Chronic Health Conditions is easy to understand with generous use of illustrations, tables, and charts. Although this book was written for healthcare professionals, it is just as suitable for parents of children with special needs who would like to participate in exercise or sports.

Excerpts reprinted with permission.

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WHAT'S HAPPENING

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The Food Allergy Network(FAN) releases books for young readers and teens

The Food Allergy Network, a national nonprofit organization established to increase public awareness about food allergies and anaphylaxis, to provide education, and to advance research, has released two new books. The first book, *Stories from the Heart: A Collection of Essays from Teens with Food Allergies* contains essays from the United States, Canada, England, and Scotland by teens sharing their experiences with food allergies. It contains frightening experiences, tips on managing food allergies such as: how friends can help, dating, and going out to eat.

Andrew and Maya Learn About Food Allergies is a book for younger readers. Maya and Andrew visit an old professor to learn what happens in the body when a reaction occurs and travel in a time machine to meet other people who have food allergies. For more information about these two books or FAN's other books and videos for children, call (800) 929-4040 or visit their Web site at http://www.foodallergy.org.

Stand for Children Day

Stand for Children, a grassroots-based, nonpartisan, nonprofit membership organization, will host a series of events around the country to bring attention to Stand for Children Day on June 1, 2000. This organization works to give all children the opportunity to grow up healthy, educated, and safe. Members, often working through local chapters, take action year round to ensure that children in their communities receive proper healthcare, child care, education, protection, and support. For more information on how to obtain a Stand for Children Day Event Planning Kit or a membership brochure, contact Stand for Children: 1834 Connecticut Ave., NW, Washington, D.C. 20009; Phone: (800) 663-4032; Fax: (202) 234-0391; Web site: http://www.stand.org; or E-mail: tellstand@stand.org.

United States Postal Service and Special Olympics unveil stamp

The United States Postal Service and Special Olympics will unveil the new Special Olympics stamp, the latest of the "Celebrate the Century" series. The unveiling will take place during the Opening Ceremonies of Special Olympics' Florida Summer Games and are scheduled to be issued to the public on May 2, 2000. The stamp was selected as a result of public balloting last year and is one of 15 commemorative stamps saluting the 20th century.

Special Olympics is an international,

continued on page 24

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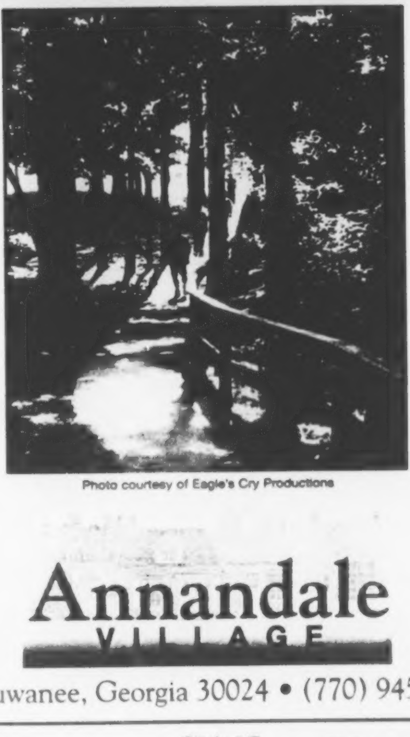

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continued from page 22

year-round program of sports training and competition for individuals with mental retardation. More than one million athletes in over 160 countries train and compete in 25 Olympic-type summer and winter sports. Special Olympics provides people with mental retardation continuing opportunities to develop fitness, demonstrate courage, and experience joy as they participate in the sharing of gifts and friendship with their families and community. For more information visit Special Olympics at http://www.specialolympics.org.

Product recall information

In cooperation with the U.S. Consumer Product Safety Commission (CPSC), InSTEP LLC, of Mendota Heights, MN is recalling about 44,000 jogging strollers. The stroller's brake can fail, causing the stroller to unexpectedly roll over resulting in injury to the child. The recall involves InSTEP and HEALTHRIDER brand single and double jogging stroller manufactured from December 1998 through July 1999.

Consumers should stop using the strollers immediately and contact InSTEP LLC to receive a free, easy-to-install repair kit. To order the repair kit or for more information, call InSTEP LLC at (800) 242-6110 between 8 a.m. and 5 p.m. CST, Monday through Friday, or access the company's Web site at http://www.instep.net.

In cooperation with the CPSC, Playskool, of Pawtucket, RI, a division of Hasbro, Inc., is voluntarily recalling about 273,000 spill-proof cups. The flexible spout on the cup can tear between the slitted opening, causing a small piece of material to come loose, posing a choking hazard to young children. The plastic cups are for children aged 6 months and up and include a twist-on lid that has a flexible, yellow spout. These cups were sold nationwide January 1998 through July 1999. Parents and caregivers should stop young children from using these cups immediately and contact Playskool to get a free, designed lid. To request a replacement lid or for more information, call Playskool at (888) 690-6166, or go to their Web site at http://www.hasbro.com.

The U.S. Consumer Product Safety Commission protects the public from unreasonable risk of injury or death from 15,000 types of consumer products under the agency's jurisdiction. To report a dangerous product or product-related injury, and for information on CPSC's fax-on-demand service, call their hotline at (800) 638-2772 or CPSC's teletypewriter at (800) 638-8270. Consumers can obtain this release and recall information at CPSC's Web site: http://www. cpsc.gov. Consumers can report product hazards via e-mail at info@cpsc. gov.

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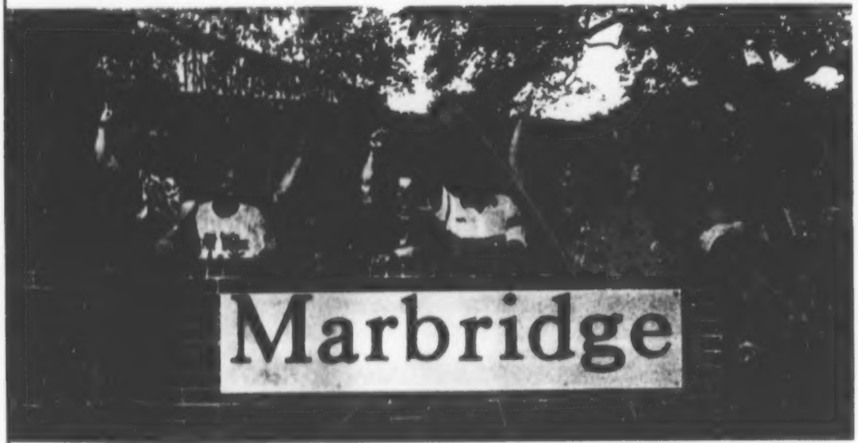

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And the Winner is...
EP's own Dennis Dusevic

"Dennis shows a great spirit, charm, independence, desire to succeed, and effort," says Dennis' instructor at CTT, Maria Ocoro. The President of APSE, Jon J. Day, presented Dennis with the award.

Dennis' proud mother, Rosa, comments on her son's award: "Dennis has always been very determined to find work. He likes to work hard and succeed. I am very proud and pleased for him."

Exceptional Parent's Information Systems Coordinator, Dennis Dusevic, 26, was recently honored by The Association for Persons in Supported Employment (APSE) with an award for personal achievement. APSE, an organization dedicated to fostering employment opportunities for people with disabilities, recognizes individuals who exhibit success in the workplace through their commitment, attitude, and reliability. Dennis trained and learned his job skills through Careers Through Technology (CTT), part of Bergen County Special Services in New Jersey. His job coach remains in contact with him to address any concerns that he may have. In addition to his work at EP, Dennis, who has cerebral palsy, works at Staples' New Jersey Headquarters updating and maintaining their telephone directory. Dennis' dedication and professionalism has earned him respect from both his employees and co-workers.

At the awards luncheon, with his mother, Rosa, job coaches, and fellow students proudly looking on, Dennis wheeled onto the stage to receive his award. "It is an honor to be receiving this award. I would like to thank the...staff at the CTT Program for the help and support they have given me, especially these last few months with my jobs; the people at Exceptional Parent magazine and at Staples for giving me the opportunity to work for their companies and being part of their staff. I also want to thank my parents for the love and support they have given throughout my life." **EP**

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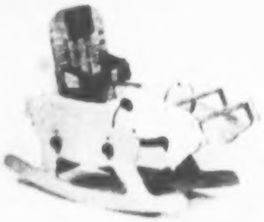

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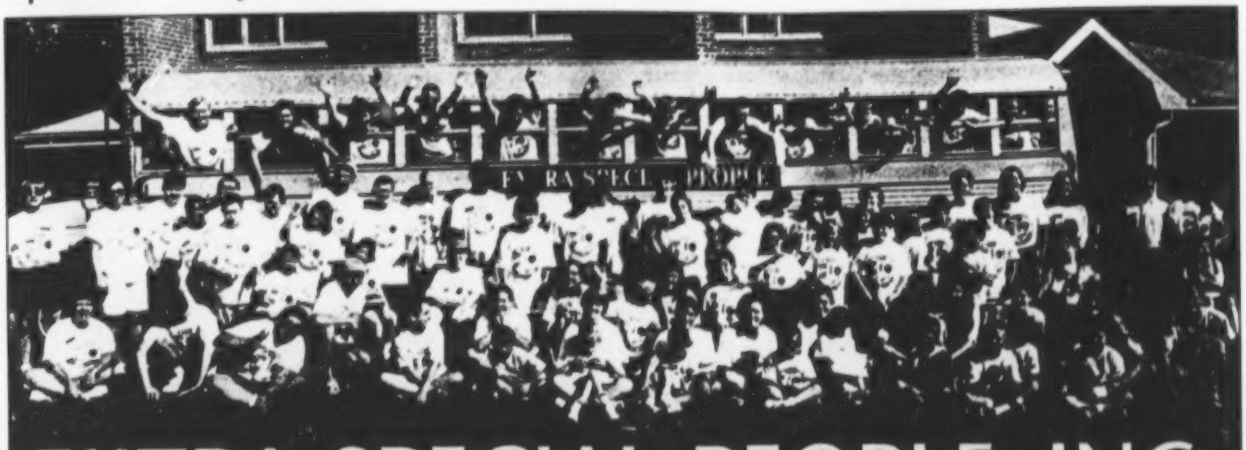


EXTRA SPECIAL PEOPLE, INC.

by Gale Jurasek

Good summer "rec" programs function as a vital link in helping a child maintain skills when school is closed and gives him or her an opportunity for fun and friendships. In addition, they provide respite for parents. Parent Carol Brooks found just such a program in Extra Special People, Inc. (ESP). In her letter, which was printed in our March "Reader's Talk" article, Carol told us all it did to help her son, Craig, who has multiple disabillities. We thought that our readers would like to know more about what creates a successful summer program like ESP, so we asked founder Martha Wyllie to tell us how it can be replicated in other communities.

If you experience an outstanding summer program this season, please write to us about it. Send your submissions before November 1, 2000, to us at: Summer Rec. Standouts, c/o Exceptional Parent magazine, 555 Kinderkamack Rd., Oradell, NJ 07649-1517; E-mail epedit@aol.com.

Obnoxious Day! Wacky Tacky Wednesday! Hay rides! Cookouts! Daily swimming, weekly bowling trips and more! These are a few items packed into the eight-week summer calendar of Extra Special People, Inc. (ESP). Located in Watkinsville, Georgia, ESP runs a summer program for children and young adults with disabilities that guarantees fun and learning for everyone involved. During the rest of the year, ESP sponsors twice-monthly bowling, outings to the zoo in Atlanta, field days, and various festivals. High on fun and energy—low on cost, ESP is a recreation program with a recipe for success. According to Martha Wyllie, "The mission of ESP is to provide meaningful learning and leisure opportunities for all developmentally disabled youth, young adults, and their families; to provide continuity between classroom and training-center settings; and to give families a support system of acceptance and understanding. . . ."

Martha, who also serves as volunteer Director, *is* ESP, according to one parent. With her tireless dedication and perseverance, she has accomplished something of great value to families in her community.

Beginnings

ESP was started in the early 1980s as a way to develop outside activities for children and young adults with disabilities and their families. It began with a bowling team, and after the match, the bowlers went out to eat at a local restaurant. Sixty families participated in those bowling trips.

The first ESP summer camp was held in 1987 and included 21 families. "Initially, the program was held in the basement of a church. The next year, we were in what used to be a holding facility for a chain gang!" Martha laughs, as she remembers, "The bars were still on the windows."

One week of the camp was (and still is) a residential overnight camp at Rock Eagle 4-H camp. Rock Eagle camp opened their facility to ESP after their own summer program finished. They also donated equipment and volunteered to help out.

As a nonprofit organization, ESP exists on donations. ESP's fundraising includes an air show in Athens, GA, a golf tournament, "buddy" walks, and other fundraisers throughout the year. According to Martha, the importance of keeping things local cannot be overemphasized. She points out that keeping activities in the community gives participants and local residents a sense of inclusion. Keeping everything local raised awareness. When ESP approached local government and businesses for help and funding, they received much of what they asked for.

Martha also attended town meetings to ask for land for a facility to be built. At one of these meetings, a councilman told her that there was some land available and to go ask the mayor. She did. The mayor thought ESP would be good for the community, and he arranged to lease some land. The ESP building, built in 1993, is 2800 square feet. Last spring, a new building was added for arts and crafts. School buses were donated from neighboring counties.

People donated their time and services, including air conditioning installation, lawn care, and fundraising. Throughout it all, the parents were always involved. Martha would ask them what they wanted from ESP. She told them, "It's your classroom—come share—be a part of it."

Get the community involved

Martha recommends getting interested people together, starting with the local government and town council. "Go to meetings and ask for things. Get the use of parks and whatever facilities you have in your neighborhood. Get people in the community involved." She continues, "When the campers first started going to the beach at Sandy Creek lake, the beach used to clear out every day when people saw the ESP bus coming. Now, no one leaves, and at the end of the week, when the counselors and campers show off what they have learned, everyone stays and watches." Martha says that having these activities in the community has made people more accepting of children with special needs.

Remaining completely open about finances is also extremely important. "When people see you are doing exactly what you said you would be doing with the money you receive, it builds trust and support. The ESP board of directors makes policy, but they also have yard sales and pitch in any way they can," says Martha.

Hard work, big payoff

Long before the summer begins, Martha and camp volunteers are busy preparing. Volunteers teach the counselors the skills they need. They discuss confidentiality and disability issue's, and provide training for the counselors. This takes place during a week-long counselor orientation program. Counselors are given basic training such as first aid, CPR, and how to transfer an individual into and out of a wheelchair.

The camp staff also works with the children's schools to provide educational continuity. Camp staff visit each camper's school and the child's Individualized Education Plan (IEP) team to find out what they should continue working on during the summer.

The staff is made up of undergraduate and graduate students, many from the University of Georgia, majoring in special education or related fields. Teachers and high school students also work at the camp. At the end of the first week of camp, all of the counselors must write down three "gifts" (valuable learning experiences) they received that week. They must hand in their lists every Friday. At the end of the camp year, these lists are returned to each counselor so they can see how they have grown during the summer.

The camper application for ESP is detailed, including a medical history of the camper, medications and when they must be taken, as well as a medical release form. There is also a section asking about the camper's favorite activities, sports, whether he or she is active or shy, and any assistance he or she will need during the day.

Above: two campers hang bird feeders that they made; Left: a Shawnee-painted counselor with a camper during Rock Eagle 4-H residential camp week.

Martha says that the campers help with everything. "They move furniture, garden, and have cooking festivals celebrating different nations' cultures. They learn camping songs, have arts and crafts, swim every day, and have a great time while learning. Everything ESP does has a teaching element."

"The ultimate purpose of ESP," says Martha, "is to provide comfort for the parents, to serve the family and serve the town." Parents can drop their children off for the day with complete confidence. Martha explains that the most difficult part of running the program is turning families away because of lack of space. The current ESP facility can accommodate 45 campers at one time, with 33 staff members. Campers can also apply for staff positions.

Parents are always welcome, and the parents of campers are given the option of meeting with the entire staff during orientation week to discuss their child. Says Martha, "We are a program for families." **EP**

Making a difference

According to Carol Brooks, whose son Craig has multiple disabilities, "[He] never had the opportunity to experience 'camp.' However, he attended his first camp (at ESP) at age seven and gained more in eight weeks than he had in his entire lifetime. ESP is staffed by the most energetic, remarkable young people I have ever had the privilege of knowing. Craig went swimming at Sandy Creek and bowling at Showtime, where he received a trophy for scoring 180 points. He took several field trips, including one all day to Zoo, Atlanta; he received three ribbons at Field Day; made a wall hanging for his room, and a t-shirt for his sister in crafts. He went to the library for story time and on a hayride and a cookout. But most of all, Craig had fun and made many new friends. I never thought Craig would ever get to camp, but he did it!"

A camper with cerebral palsy wrote in the ESP brochure, "I hesitate to tell people about CP but not at ESP because there I receive love and acceptance. If I had not gone to Rock Eagle 4-H Camp, I would not have climbed a tree for the first time at age 17. It doesn't matter if you are in a wheelchair at ESP Camp. Anything is possible."

SPECIAL OLYMPICS

Warming Up to Recreational Activities

Special Olympics Motor Activities Training Program gets everyone moving with easy stretching

PHOTO AND IMAGES COURTESY OF SPECIAL OLYMPICS

Whether or not an individual can participate in sports, warm-up activities are a great opportunity for exercise. The Special Olympics publishes training guides for all its sports activities, and provides the "Motor Activities Training Program Guide" for individuals who are not yet ready to train for a sport. The Guide offers some basic exercises and tips for encouraging movement, which have been developed and tested by professionals with practical experience in working with people with severe motor learning problems. The following excerpts from the Guide highlight some light warm-up activities that we will expand upon in upcoming issues. (Note: No exercise program should be started without physician approval.)

Tips for getting started

- Individuals who may not have the mobility or range of motion to work vigorously for sustained periods can still participate in warm ups. Participants should be encouraged to develop as much independent movement as possible—translating into a greater exercise benefit.
- Add music and musical objects, brightly colored objects, and objects with differing textures in the warm-up program to stimulate the participant's senses. These additions heighten interest in the activity and promote the participant's awareness of surroundings.
- Many individuals who have muscle spasticity may have decreased flexibility which limits range of motion. Individuals who can consciously relax their muscles and body may benefit from relaxation exercises. Other participants may respond to relaxation techniques such as slow rocking, rhythmical rotation of the trunk, and gentle shaking of the limbs. Relaxation exercises and techniques are most effective when combined with slow, sustained stretching activities.
- All participants, regardless of their disabilities should wear clothing that is appropriate for exercise and sports. Proper athletic clothing can set the tone for physical activity and training., make participants feel included and it allows them to work on functional dressing and grooming skills.

Proper clothing for participation in the Motor Activities Training Program should include: loose fitting t-shirts, shorts, socks, and sweat clothes made of cotton or breathable fabric, and sneakers or other types of athletic footwear. Participants who wear braces, prosthetics, or other types of devices may require some modifications.

Breathing exercises

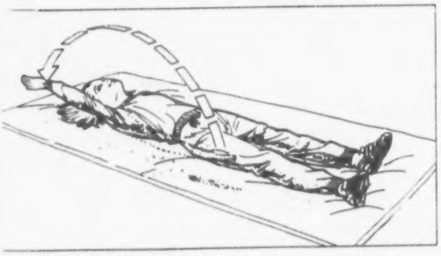
- Place participant in his/her most comfortable and functional position.
- Provide support to participant's head, shoulders, etc., as needed.
- Face participant and gain his/her attention.
- Demonstrate inhaling deeply and holding it.
- Ask participant to inhale deeply and hold it.
- Demonstrate forceful exhaling.
- Ask participant to forcefully exhale.
- Repeat five times.

Relaxation

- Place participant in his/her most comfortable and functional position.
- Provide support to participant's head, shoulders, etc., as needed.
- Face participant and gain his/her attention.
- Using a soft towel, yarn ball, Nerf® ball, or other soft object, gently rub the object up and down participant's arm.
- If participant's range of motion permits, assist him/her in holding the object and touching it to his or her arm, leg, foot, etc.

Independent muscular relaxation techniques on all major muscles groups

- Take participant out of wheelchair and place him/her on a mat.
- Support participant's head, shoulders, and body as needed.
- Face participant and gain his/her attention.
- Explain to participant that you are going to work on relaxing his/her body.
- For participants who are aware of their body and have some neuromuscular control, ask them to think about first tightening a muscle and then relaxing it (e.g., tighten the muscles of the front of the arm, then let all of the air out of it and relax the muscle).
- Muscles should be contracted (tightened) for 5 seconds then slowly relaxed for 15 seconds.
- Repeat with all major muscle groups.



Independent stretching

Upper-body stretching:

- Have participant lie down on mat on his/her back with arms to side of the body.
- Have participant lift one arm up over his/her head until the arm touches the mat behind (or as far as possible). Encourage keeping arms as straight as possible and hold stretched position for 10 seconds.
- Slowly bring arm back down to starting position, then repeat with other arm.

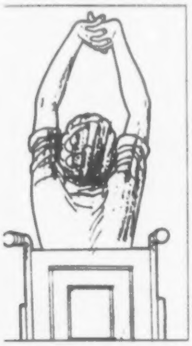
Hip stretching:

- Have participant lie down on mat on his/her back. Have him/her bring one knee towards his/her chest while grasping knee with both hands. Encourage him/her to pull knee as close to chest a possible and hold stretched position for 10 seconds.
- Slowly bring leg back to starting position, then repeat with other leg.

Inside of leg stretching:

- Have participant lie down on mat on his/her back with legs together.
- Have him/her slowly move one leg outward away from body. (For some participants, it may be easier for them to move both legs at the same time.) Encourage participant to stretch legs out as far as possible and hold position for 10 seconds . Slowly bring legs back to starting position, then repeat a second time.

INDEPENDENT STRETCHES PERFORMED IN A WHEELCHAIR



Trunk stretching:

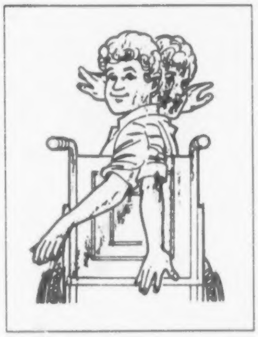
- From sitting position, have participant reach around chair with one arm and tuck elbow around back hand holds of chair. Have him/ her then turn head to look behind and reach across his/her body with other arm. Encourage him/her to stretch as far as possible and hold stretched position for 10 seconds . Slowly bring arm and body back to starting position, then repeat to other side.

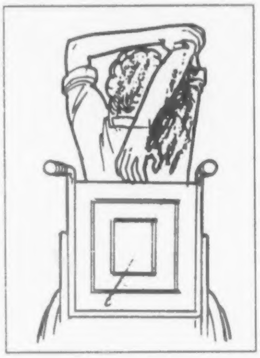
Upper-body stretching:

- From sitting position, have participant clasp hands together, then slowly reach up over his/her head as far as possible. Encourage participant to straighten out arms as much as possible and hold stretched position for 10 seconds.
- Slowly bring arms back to starting position, then repeat a second time.

Back and arm stretching:

- From sitting position, have participant clasp hands behind back. Then have him/her lean forward slightly, as far as possible, while lifting hands up as far as possible.





- Hold stretched position for 10 seconds, then slowly bring body back to starting position.

Shoulder and arm stretching:

- From sitting position, have participant bring one arm back behind head and back. Encourage him/her to use other hand to grasp elbow and gently pull arm back as far as possible.
- Hold stretched position for 10 seconds and slowly return to starting position. Repeat with other arm. **EP**

Next month, look for more activities from Special Olympics. For more information contact:

Special Olympics International
1325 G St. NW, Ste. 500
Washington, DC 20005
(202) 628-3630 • (202) 824-0200 (fax)
🖂soimail@aol.com • http://specialolympics.org

Adaptive Recreation Organizations

Here are a few national organizations offering adaptive sports and recreation activities for people of many abilities. In addition to providing a variety of opportunities for fun and social interaction, some of the listed organizations offer support groups as well. Most of the organizations have local chapters, or they can do referrals to other local organizations which offer similar activities.

AIM for the Handicapped (Adventures in Movement for the Handicapped)
945 Danbury Rd.
Dayton, OH 45420
(800) 332-8210
(937) 294-4611
(937) 294-3783 (fax)
🖂aimkids@siscom.net
🖂bookstore@aca-campus.org
http://www.acacamps.org

National Center on Physical Activity and Disability (NCPAD)
1640 W. Roosevelt Road
Chicago, IL 60608-6904
(800) 900-8086
http//:www.ncpad.org

Disabled Sports USA
451 Hungerford Dr., Ste. 100
Rockville, MD 20850
(301) 217-0960
(301) 217-0968 (fax)
🖂dsusa@dsusa.org
http://www.dsusa.org

National Ability Center (NAC)
P.O.Box 682799
Park City, UT 84068-2799
(435) 649-3991 (voice/TDD)
(435) 658-3992 (fax)
🖂nac@xmission.com
http://www.nationalabilities-center.org

National Center on Accessibility
University of Indiana
5020 State Rd. 67 N.
Martinsville, IN 46151
(765) 349-9240
(765) 342-6658 (fax)
🖂nca@indiana.edu
http://www.indiana.edu~tildanca

United States Cerebral Palsy Athletic Association
25 W. Independence Way
Kingston, Rhode Island 02881
(401) 874-7465
(401) 874-7468 (fax)
🖂usdpaa@mailbbsnet.com
http://www.usapaa.org

Association of Blind Athletes (USABA)
33 N. Institute St.
Colorado Springs, CO 80903
(719) 630-0422
(719) 630-0616 (fax)
🖂usainfo@iex.net
http://www.usaba.org

US Wheelchair Weightlifting Association
39 Michael Pl.
Levittown, PA 19057
(215) 945-1964
(215) 946-2574 (fax)

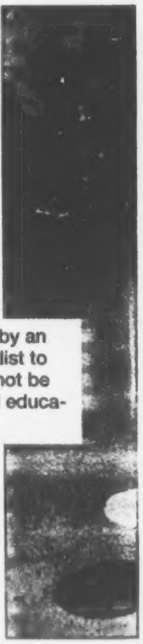
LET'S GET PHYSICAL

Adapted Physical Education

Adapted physical education is federally mandated according to special education law. The law states: "...physical education, specially designed if necessary, must be made available to every student with a disability receiving a free appropriate public education." Adapted physical education services should be a part of the Individual Education Plan (IEP) of every student who is eligible. All states and public schools must comply with this federal law.

According to the National Consortium for Physical Education and Recreation for Individuals with Disabilities (NCPERID), "Qualified teachers with appropriate state-approval, certification, license, or credential in adapted physical education should plan, implement, and evaluate physical education instruction for students with disabilities. Many states have specific qualifications or standards for adapted physical education teachers. In states without established adapted physical education professional standards, qualified personnel should implement adapted physical education. National standards for adapted physical education teachers have recently been developed through a project of NCPERID sponsored by the U.S. Department of Education-Special Education Programs. National Certification in adapted Physical Education is now available to qualified physical education teachers through NCPERID."

In the following articles, three teachers of adapted physical education share their approaches to serving children and adolescents with special needs. These individuals are working within their school districts to ensure that adapted physical education is available to those students who are entitled to it.—the Editors



Learning Movement Through Play

by Rebecca K. Lytle, PhD

Physical activity is critical to the health and well-being of every individual, and it is even more important for children with disabilities. Adapted physical education (PE) can help children master the skills they will need for daily living, such as walking, running, stair climbing, transferring, and wheelchair mobility. In addition, adapted PE programs help children develop skills for participation in recreational and sport activities within their communities, preparing them for a lifetime of positive, playful activities.

The interactive nature of any PE program helps to develop a child's social and communicative skills, as well as self-esteem. In addition, PE can improve respiration and circulation and thereby reduce the incidence of upper-respiratory infections and digestive problems.

My experience as an adapted PE teacher included a child named Sarah, who had a form of muscular dystrophy. When she was born, Sarah's parents were told that she would not live very long. Sarah, however, grew up and entered elementary school. I started working with Sarah when she was in the 4th grade and using a power wheelchair. During her twice-weekly adapted PE classes, Sarah and I played various games designed to maintain her upper-body strength and increase her respiration. Some of these games included balloon volleyball and Ping-Pong hockey (where a Ping-Pong ball is moved toward the opponent's goal by blowing air at it through a straw). In addition to these individual activities, Sarah also participated in regular PE classes with her peers. During

Adapted PE services are provided by an adapted physical education specialist to students who have needs that cannot be adequately satisfied in other physical educational programs.

these classes, I collaborated with the regular PE teacher to make necessary rule modifications or variations for Sarah. I continued to work with Sarah throughout high school on her range of motion, strength, and aerobic capacity.

Sarah later went on to compete in the regional cerebral palsy track and field games. I thought this would be a positive challenge for Sarah (although she did not have cerebral palsy, these games are open to people with many different types of disabilities). Sarah did outstanding in the regional games and qualified to go to the National Les Autres games in Texas.

Sarah's participation in adapted PE

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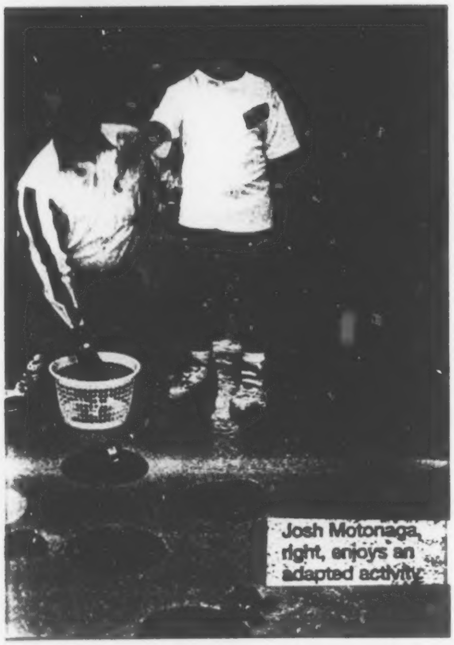

Josh Motonaga, right, enjoys an adapted activity.

On His Way To A Brighter Future

Michael is an inquisitive boy with mental retardation. His behavior kept him from making progress in public school. His frequent hitting, biting, and noncompliance pulled him further and further behind, and no one knew how to get him back on course.

When he came to Heartspring School at the age of 10, we started by getting to know him as an individual. His interdisciplinary team gathered data on his behavior in every situation, throughout the day. We documented causes and correlations.

Patterns began to emerge. Michael's toughest challenges, it turned out, lay in making transitions between tasks, so we provided him with structure and predictability. He was a boy of many hobbies, so we reinforced appropriate behaviors with rewards that reflected his personal interests. He had fallen into a cycle of frustration that tended to snowball out of control, so we taught him practical strategies dealing constructively with his anger.

Now, just over a year later, Michael is realizing a fuller potential. He's happier. His frequency of problem behaviors has dropped from 85 percent to nearly zero. He's returned to public school – and is once again moving forward with his life.

If you know a child who could use some help getting back on course, call Heartspring School.

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Circle #18

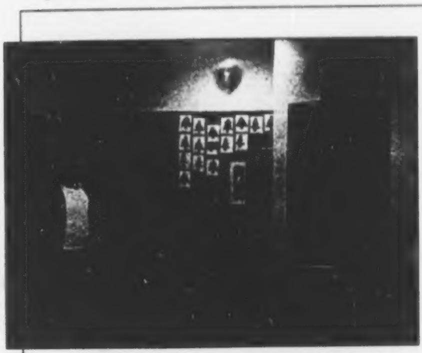


PHOTO BY MIKE AITKEN

Carlos Rodriguez, 8 (left) and a friend play a variation of balloon volleyball.

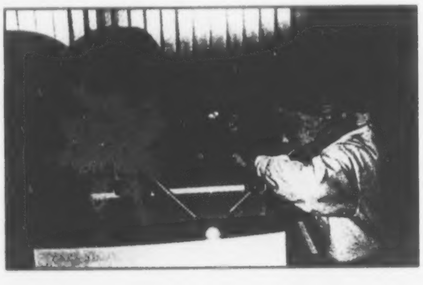
I. Balloon Volleyball (one on one)

Goals: Develop eye-hand coordination, visual tracking, range of motion of the upper extremities.
Equipment: 2-4 balloons (always have extra in case they pop), table and chairs
Rules: Players are seated opposite each other at a table which serves as the court. One person serves. The object of the game is to keep the balloon in the air for as many hits as possible. Each player may only hit the balloon one time before it must go across the table to the other player. Each time the balloon is dropped, the other player begins by serving the ball. The challenge is to continue to rally the balloon for more and more consecutive hits.

Variations:
1. Play with more players per side.
2. Can allow more than one hit by the same player.
3. Play with more than one balloon.
4. Play competitively as in the rules of traditional volleyball.
5. Use a larger or smaller table for the court, or play over a jump rope placed on the floor.
6. Use a beach ball for highly skilled players.
7. Can play the balloon off a bounce on the table or floor.
8. Can be played by hitting the balloon with a paddle.
9. Can be played off any body part or using a head stick.

II. Ping-Pong Hockey

Goals: Develop aerobic capacity, breath control, visual tracking.
Equipment: 2 straws, 1 ping-pong ball, empty shirt box, scissors, marking pen.
How to make the court: Any gift box about the size of a shirt box. Cut a hole for a goal in the end panels of the box. Then draw a line across the middle of the bottom of the box to indicate the center court.
Rules: Place the hockey box on a table where all players can reach it with their straws. Play begins by dropping the ping pong ball in the center circle of the court. Players then try to blow the ping-pong ball into the opponent's goal. Players may not touch the ball with the straw. Each time the ball drops through the opponent's goal, 1 point is scored.
Caution: This is a game that might be used as a warm-up activity or with frequent rest periods, so students do not get light headed.



Variations:
1. Play with 2 or 3 players on a side.
2. Use more than one ping-pong ball for game play.
3. Use a larger box and push the ball using the fingers, or make modified hockey sticks with cardboard.

The priority for any activity is to set it up to be challenging for the players involved and allowing them to be successful. Having fun while developing motor skills is the most important outcome!

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assisted with not only her physical development but also with the social and emotional development, as well as her self-esteem. Although Sarah did not pursue her athletic career beyond that year, we continued to work on her range of motion, strength, and aerobic capacity throughout high school. She has recently completed her BA in journalism and is currently attending law school.

Every child must receive PE as part of his or her school curriculum, with no exception for children with disabilities. The Individuals with Disabilities Education Act (IDEA), defines PE as, "The development of : a) physical and motor fitness; b) fundamental motor skills and patterns; and c) skills in aquatics, dance, and individual or group games and sports." It is important to remember that adapted PE is something that all children with disabilities have a legal right to receive, if they qualify for services. If you think your child may qualify for adapted PE services, ask your local special education program for information.

Adapted PE services can be provided in a variety of ways depending on the child's needs. Instruction may be provided solely by the adapted PE teacher in a one-on-one setting, or the child might have a combination of adapted and general PE classes. Placement options are virtually limitless.

Adapted PE is not the same thing as physical therapy (PT). Here are some of the differences:

PT

1. Traditionally, physical therapy has been defined as "a treatment that uses heat, cold, light, water, electricity, massage, ultrasound, exercise, and functional training."(Claudine Sherrill, *Adapted Physical Activity, Recreation, and Sport*—1993.)
2. Focus on functional skills
3. Stretching and range of motion
4. Treatment to remedy a problem
5. Prescriptive in nature
6. Mobility
7. Strength

Adapted PE

1. School curriculum area like math or english, or PE. It is a mandated area of instruction.

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Circle #28

restrooms

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Circle #61

RECREATION
Sports Play

Questions Parents Can Ask of Their School District

- What support services are available to make sure my child will be successful in PE?
- What are all the placement options within my county or district for PE?
- Are adapted PE consultation services available?
- If there is not an adapted PE specialist in my school district, why not? (In some cases, a district may decide that physical and occupational therapy address the gross motor needs of children with disabilities. For this reason, they do not offer adapted PE services. Keep in mind, however, that physical therapy and occupational therapy are NOT a substitute for adapted PE; they are medical services that focus on goals different from those of adapted PE.)
- Does the adapted PE teacher come into the class to support the existing PE program?
- Will the adapted PE teacher and the general PE teacher meet to plan the most appropriate curriculum for my child?
- What is the curriculum of the PE teacher? Does it support inclusion of all students? How competitive is the PE environment?
- What types of disability awareness training have been conducted at the school and in the general physical education program for both students and teachers?
- Do you have a peer tutor/training program?
- Will there be an instructional assistant there to help?
- What training does the adapted PE teacher have?

Adapted PE is a service, not a placement, and can be provided for your child in any type of placement. You are the best advocate for your child. Ask your local education district about their adapted PE and general PE services.

If you would like more information about developmentally appropriate PE and practices, contact the following Web sites:

CASPER (Concerned Adults & Students for Physical Education Reform). Contains information on appropriate practices in PE—http://www.csuchico.edu/casper/.

Project Inspire: Texas Women's University

Includes information on programming, strategies, disabilities information sheets, legislation, and advocacy—http://www7.twu.edu/~f_huettig/.

PE Central: http://pe.central.vt.edu/adapted/adaptedmenu.html.

NICHCY (National Information Center for Children and Youth with Disabilities). This Web site contains general information for families and professionals about laws and regulations. Information is also provided in Spanish—http://www.nichcy.org.

continued from page 34

2. Should be taught by an adapted PE teacher, not a physical therapist. Some states have a specialist credential program required for adapted PE teachers. Other states are requiring the new Adapted Physical Education National Standards (APENS) exam. Parents might want to ask what is required in their state and advocate for credentials of some kind for these individuals. Other states may require a teaching credential of any kind to teach adapted PE.
3. Fundamental motor skills
4. Games, aquatics, dance
5. Educational service, focused on teaching and instruction
6. Mobility
7. Develop strength, muscular endurance, and aerobic capacity
8. Functional skills for participation in activities such as walking and transferring
9. Sports training for disability sports competitions

Each is a distinct discipline and one cannot substitute for the other. However, there may be some overlap of content. Any overlap serves to reinforce learning for the student. When these two disciplines work collaboratively together student programs and learning can be enhanced. **EP**

Rebecca K. Lytle, PhD has been the coordinator for the Adapted Physical Education Program at California State University—Chico for the past six years.

BEST COPY AVAILABLE

Adapted Physical Education in High School

by Michael Aitken.

Adapted Physical Education (PE) has the same desired outcomes as a regular PE class. Both classes hope to improve physical condition, develop skills and knowledge in a variety of activities/games, develop skills in group interaction and promote the growth of other social skills. The student with special needs, however, would be at a significant disadvantage in a regular PE class because of the activity, size, competitiveness, or group dynamics of the class. In the adapted PE class, the focus is on age-appropriate activities but with adaptations to enhance the development of each student's skills. Another area that adapted PE addresses, especially at the high school level, is interaction with peers.

The technique for teaching adapted PE that I use for my students is a "peer-pal" approach. This works on the premise that doing age-appropriate activities is secondary to having age-appropriate peers. Having the students working with peers in their own age group (teenagers) is more important to socialization, particularly during adolescence. In a regular PE class, we develop not only the physical conditioning and skills for athletics and recreational play, but also many of the social skills that are necessary for successful interaction throughout our lives. The older the student and the more severe the disability, the further these social behaviors are delayed because of lack of participation and interaction with peers. If social behavior does not develop, the individual becomes more isolated. It is the development of socially acceptable behavior that is most critical to the advancement of the student, especially during adolescence.

My adapted PE class is a mix of physical activity and socialization. The class meets for 80 minutes every other day. 80 minutes is too long for non-stop exercise, so the class takes time out for talking and socializing with peers. We also go on bowling, ice-skating, and swimming trips to public settings outside school.

The ultimate goal of the adapted PE class is to have the students mainstreamed back into regular PE classes, which they would attend with a peer pal, who would provide emotional support and assistance with skills and other situations as needed. The student, after being mainstreamed into regular PE, would still be invited on the trips with the adapted PE class.

Above: Adapted PE students Adam and Derek about to return the ball in a volleyball-type game; left: Samantha, with peer-pal Erika, make their way through an obstacle course.

The greatest benefit from adapted PE is obtained when there is constant communication between the teacher, parent(s), counselor, therapist, job coach and any others involved in the student's care. This should all be part of the student's Individual Education Plan (IEP), and, ideally, should be available from pre-school on. From my experience, however, PE for students with disabilities is often considered an "extra" that is not necessary unless it happens to fit conveniently in with a pre-existing adapted PE program–often not even available until the student is in high school.

If we believe that adapted PE can improve physical skills and social behavior, then it must (and very likely will) be the student's best chance to succeed in the future, both at work and in social settings.

One of my students was a freshman boy with antisocial behavior, unsteady gait, poor eye/hand coordination, stooped posture, and inappropriate emotional responses (he would get disproportionately angry when he could not catch a ball, for example). In the adapted PE class, he was in a small class with peer pals, and was given activities that focused on developing hand/eye coordination. He worked on strength and conditioning as well. His self-esteem improved, and, because of the peer-pal setting, he began to behave like a typical teenager. When he was mainstreamed into the regular PE class, he was able to participate successfully.

Although success in the school setting is helpful, what is most important is that the child will be better prepared for living outside of school. It has long been understood that play develops social behavior, yet many schools have not developed this aspect of a special needs student's education, or else they do not start a program until the student is in the higher grades. Through directed organized play, these students can begin to break away from isolation and stereotyping and gradually work toward realistic and positive inclusion. **EP**

Michael Aitken is a Physical Education & Wellness Instructor at Hall-Dale High School in Farmingdale, Maine. He also teaches an adapted PE class there.

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A Positive SPIRIT

by Gale Jurasek

John Passarini and Andrew Pilkington, who is in the second grade, in the inclusive PE class that Passarini co-teaches.

Adapted physical education (PE) is a service that, by law, must be provided to every child with special needs. When a child in an adapted PE class enjoys learning, and looks forward to the next class, the philosophy underlying adapted PE becomes clear. In the words of John Passarini, "Adapted physical education is based on a belief in the dignity and value of each human being. Furthermore, it includes a belief that each individual has an ability and desire to move, and be active, and that activity is a necessary component of a healthy lifestyle."

John Passarini is a nationally certified adapted PE teacher and has been the adapted PE specialist for the Wayland Public School District in Wayland, Massachusetts for the past 12 years. He uses a model called "reverse mainstreaming," where each child brings a guest to class, so that half of the students are children with disabilities. He then works on activities that the whole class can do together. This method provides opportunities for development of both motor and social skills. Passarini has noticed that it is an extremely positive experience for all of the students involved, and gets calls from parents of students without disabilities asking that their children be included. He has seen fun activities, games, and friendships carried over from the class to other environments, such as the playground and even the community. With the reverse mainstreaming method, teachers have to make adjustments in the guest students' class schedules, but Passarini notes that the teachers he deals with have all been very supportive.

Doris Goldthwaite, PhD, director of Student Services at Wayland Public Schools, wrote of Passarini's reverse mainstreaming method, "His program model is not one of pulling out a small group of disabled students to play games together. Instead, he extends the concept and practice of inclusion by encouraging each targeted student to invite a group of typical classroom peers to join in the [adapted PE] activity of the week, thus providing social role models and gradually building an inclusive community around the student with the potential to extend into classroom, lunchroom, and recess environments."

Adapted PE should begin in early childhood. "It is the foundation for any physical activity a child will perform during his or her life. If a child does not develop a certain level of maturity regarding fundamental motor skills, he or she will most likely become a sedentary person." He also points out that self-esteem often suffers in a regular PE class—it is difficult for children to stay positive when they are constantly reminded of their own limitations.

Below left: Passarini and Nick Stavropulos on a tandem bicycle for the sixth grade annual 9-mile bike trip to Walden Pond. Right: Passarini works on striking skills with Tina Love, who is in the eighth grade.

Adapted PE activities

One method he uses to teach striking skills illustrates the success that can be achieved by making a simple change in an object, in this case, a balloon. "I teach striking skills by taking a helium-filled balloon and removing enough helium so that the balloon

Goals and Objectives for an Adapted Physical Education IEP

The following example provides an overview of the information areas included in an adapted physical education IEP.

by John Passarini

Overview

Johnny has made a positive and effective transition into his middle school physical education environment. He attempts all activities and maintains a positive attitude.

Areas of Strength

- Enjoys most forms of play and physical activity
- Responds well to praise
- Is willing to attempt all activities
- Prefers inclusive and normalized movement environments

Areas of Need

- Bilateral coordination
- Muscle tone and muscular strength
- Understanding abstract concepts around play
- Locomotor skills (run, skip, hop, jump, etc.)
- Object control skills (catch, throw, strike, kick, etc.)
- Degenerating visual skills

Student Instructional Profile

How the student learns effectively and how the teacher can facilitate learning.

Approach to Learning

- Appreciates verbal and visual clues
- Enjoys verbal praise and rewards for achievement
- Enjoys peer support

Instructional Approaches and/or Classroom Modifications

- Needs verbal and visual clues before attempting a new task
- Benefits from practice before attempting a new game, activity, or task
- Review directions and rules frequently

Goals and Objectives

What the student can achieve through adapted PE and what the teacher plans for the student to do to achieve the goal.

ANNUAL GOAL #1: To improve physical fitness

Objective 1: Johnny will participate in 20 minutes of moderate to vigorous physical activity, 3 times a week, outside of the school day (walk, bike, swim, fitness video, etc.)

Objective 2: Johnny will improve his walking skills (gait, form, posture, speed, and endurance)

ANNUAL GOAL #2: To improve in all areas of fundamental motor skills and age-appropriate group and recreational games and activities

Objective 1: With modifications and support, Johnny will complete the full battery of the middle school fitness activity and testing unit.

Objective 2: Johnny will throw a tennis ball with age-appropriate form and technique (a downward arc of the throwing arm during the windup phase of the throw, proper rotation of the hips and shoulders, and proper transfer of weight by stepping with the foot opposite his throwing hand).

Johnny will participate in 75% of the middle school regular PE curriculum.

EVALUATION: Same for both goals

TEACHER REPORTS: Mid-year and at annual reviews

CONSULTATION WITH REGULAR PE: Monthly

Service Delivery

Type of service: Adapted PE in regular PE setting
Person responsible: Adapted PE instructor/Assistant teacher
Frequency/duration: Two 42-minute classes
Location: Gymnasium

---

hangs at the child's eye level. Once the helium is adjusted, air is blown into the balloon to make it firm. This balloon will now provide 'hang time' to allow children to catch, strike, hit, and throw balls, frisbees, or bean bags at it." The balloon is also useful for activities a child can work on at home. "If a physical therapist tells me that my student has low muscle tone and weakness in the trunk and shoulders, I send a home-activity instruction sheet home that describes proper positioning and form for fun and enjoyable balloon striking activities."

In his adapted PE classes, Passarini finds ways of modifying a child's environment, making it fun, and getting him or her ready for participation in group activities. It is important to keep in mind that movement does not come easily to all children. The more severe the disability, the more specialized the adapted PE must be.

Passarini elaborates on the importance of preparing the environment:

text continued on page 52
sidebar on page 42

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SIDEBAR

EXCEPTIONAL PROFESSIONAL

The experience of John Passarini

In February 2000, John Passarini was awarded the Adapted Physical Education National Teacher of the Year award by the American Association for Active Lifestyles and Fitness/Adapted Physical Activity Council (AALF/APAC), an affiliate of the American Alliance for Health, Physical Education, Recreation, and Dance (AAHPERD). According to Tim Davis, President Elect of APAC, the award is given to one adapted PE teacher who is selected from among each participating states' adapted PE teachers of the year. As the award recipient, "John Passarini will be APAC's representative for the year, and will share his experience and knowledge, consulting with schools throughout the country." Davis goes on to say that, "Adapted PE is a direct service under IDEA [the Individuals with Disabilities Education Act]. Parents and their children deserve to have this service provided by a qualified adapted PE teacher or a regular PE teacher who has received training in working with children who have special needs."

John Passarini's accomplishments are numerous and illustrate the dedication he has toward his students and their families. In 1994, John Passarini established and was the first director of an inclusive summer camp for children from pre-school through fifth grade, called the Pegasus Summer Enrichment Program, which meets the needs of his adapted PE students outside of school and now serves over 250 children each year. He also founded a chapter of the "Best Buddies" program at Wayland High School, to help high school students with and without disabilities integrate in social settings. In 1999, he was awarded a Wayland Public School Foundation Grant of $2,000 to initiate the Wayland Family/School Tandem Bike Program. The grant money was used to purchase two tandem bicycles, which were used during the sixth grade's 9-mile bike trip to Walden Pond. Students with disabilities who used to have to ride in vans were now able to ride on the tandem bicycles.

Evi Trefts, the mother of Nick Stavropulos, who has Down syndrome, remembers the day her son rode on a tandem bicycle with John Passarini to Walden Pond. She said that it was something the entire sixth grade did, and that if Nick had not been able to ride on the tandem bike, it would have been a disappointing start to the school year for him. Thanks to John Passarini, he was able to participate. Evi says, "He knows his kids so well. He's been so creative in the games that he's thought up to motivate Nick. He really works at keeping Nick moving and wanting to move. Nick adores him."

Passarini's devotion, exuberance, and outstanding service in adapted PE have led us to recognize him as an EP Exceptional Professional and offer him our congratulations on an award well deserved.

• Volume 1 No. 6
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The first track will be for physicians and other healthcare professionals. Emory University will offer CME (Continuing Medical Education) credits while Emory and other institutions will offer CEU (Continuing Education Units) accreditation. A basic objective is that the practitioner takes away from this meeting a new understanding of managing the patient with a disability in today's complex, time-sensitive healthcare environment. Areas of primary focus for this inaugural conference include: newborn screening; neurology, epilepsy and seizure disorders; mitochondrial disorders and inborn errors of metabolism; ADD/ADHD; autism and PDD; nutrition issues; mental retardation and developmental disabilities; and movement disorders such as spasticity, myoclonus, tics, and the dystonias.

The second track will be designed for the education community. This will include sessions for special education teachers, mainstream educators, disability service providers, and all those involved in the educational development of children and adults with chronic disorders. CEU accreditation will be offered through the Council for Exceptional Children. Topics will include access, inclusion and mainstreaming; IDEA and the Individual Educational Plan (IEP); assistive technology; learning disabilities; behavioral interventions and ADD/ADHD; autism; and family involvement in the educational process.

Increasingly, responsibility for healthcare management is devolving to the consumer, so families and other caregivers must be extraordinarily well informed about all aspects of healthcare, especially those relating to people with disabilities. Therefore, the third track is being designed for direct support professionals, families, caregivers and people with disabilities. Issues of advocacy and patient rights will be one theme, incorporating sessions on health insurance, government benefits, and access to programs. Another theme will be issues affecting the family and individuals, including caregiver burnout; lifelong medical planning; long-term financial planning; and social life, sexuality and recreation.

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SPEAKERS MAKE THE CONFERENCE

The Educational Program of the World Congress & Exposition on Disabilities(WCD) has a world-renowned faculty, offering a level of education and insight into disability issues that has never before been possible at one conference. Here are just a few of the distinguished speakers and their topics.

Neil Shulman, MD—the original Doc Hollywood—will talk about using humor as a tool. Screening newborns for inborn errors of metabolism and for hearing problems will be discussed by speakers including Paul M. Fernhoff, MD, Emory University, Ed Naylor, PhD of the University of Pittsburgh, Charles Roe, MD, of Baylor, and Marshalyn Yeargin-Allsopp, of the Centers for Disease Control and Prevention. Leading a session on mitochondrial disorders are Salvatore DiMauro, MD and Darryl DeVivo, MD, both of the Columbia College of Physicians and Surgeons. Isabelle Rapin, MD, of the Albert Einstein College of Medicine, is part of a panel on autism.

In the educational arena, a team from the Frank Porter Graham Child Development Center of the University of North Carolina-Chapel Hill will talk about inclusion programs and how best to assess them. Transitioning will be discussed by George Jesien, Executive Director of the AAUAP and colleagues, and Frank Murphy of the National Down Syndrome Congress will head a panel on IDEA and IEPs.

Course topics for families and direct support professionals will include financial planning, lifetime medical care planning, legal rights and benefits issues. Caregiver burnout is a session sure to be of interest; it will be led by Suzanne Mintz, who founded the National Family Caregivers Association as a result of her own experience.

In total, 90 hours of education in 36 sessions will be presented. As the mission of WCD is to bring the disability community together, any conference registrant can attend any session. The complete conference program can be found at www.wcdexpo.com.

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Circle #26

Seven-year-old Bonnie was part of the Oradell, NJ, Challenger Baseball League all season. Bonnie, who is virtually non-verbal and does not have a diagnosis, never showed any outward sign she was even getting anything out of the weekly games. Then, on the second-to-last game of the season, as one of the players hit a ground ball, Bonnie broke away from her mother, picked up the ball and threw it to first base. According to Challenger coach Terri Del Greco, "We screamed, we cheered and cried. It was just so wonderful." Accomplishments like Bonnie's are what makes Challenger League the success it is today.

CHALLENGER BASEBALL

A League of Their Own

by Kerry Pianoforte

Roger Hoffman and his son Ben enjoy a day on the field.

Baseball for all

Founded 10 years ago, Challenger League is a division of Little League baseball. It is designed to allow children with physical and mental disabilities to participate and benefit from playing baseball. Challenger League is a fun and effective way to get children with special needs involved in sports in a non-competitive setting. Each Challenger team consists of 8-12 players. Each player has a buddy who helps him or her. Buddies help players hit the ball, run the bases, and pay attention while they are in the field. The buddies can either be volunteers from local schools or parents. Terri's husband, Steven, coaches, and older son, David, 16, is involved in the games as well. Terri says, "Sometimes there are more people on the field than there are in the stands. The majority of the kids need one-on-one attention."

Children can either hit from a tee-ball stand or be pitched to by a coach. The entire team gets up to bat each inning and no score is taken. The focus is on having a good time and allowing each child to challenge his or her abilities. The teams play other local teams and travel to play games in neighboring towns. Terri notes, "It is fun for the kids to travel, see other towns, and meet new kids. They remember each other from year to year."

Catching Challenger fever

Terri found out about Challenger after reading about a league in a neighboring town. She felt that her son Stevie, who has autism, would benefit from the stimulation. Stevie, then 7, had never participated in sports before, so Terri signed him up. Through her research Terri learned that all Little Leagues are chartered to have a Challenger division. Then she began working to form a Challenger team for her own town for the next season.

According to Terri, "I was motivated because this was something that I wanted to do for my son. I also felt that this would be something that would be good for the town." Terri says the local Little League was very supportive. In the first season, Terri's Oradell division had one team. The following year, however, so many more children signed up that they started a second team. By the fourth year a third team was added. Roger Hoffman,a coach for one of the new teams and the father of a son who has a disability says, "As parents of a child who has special needs, we are always looking to broaden his experiences and to participate in

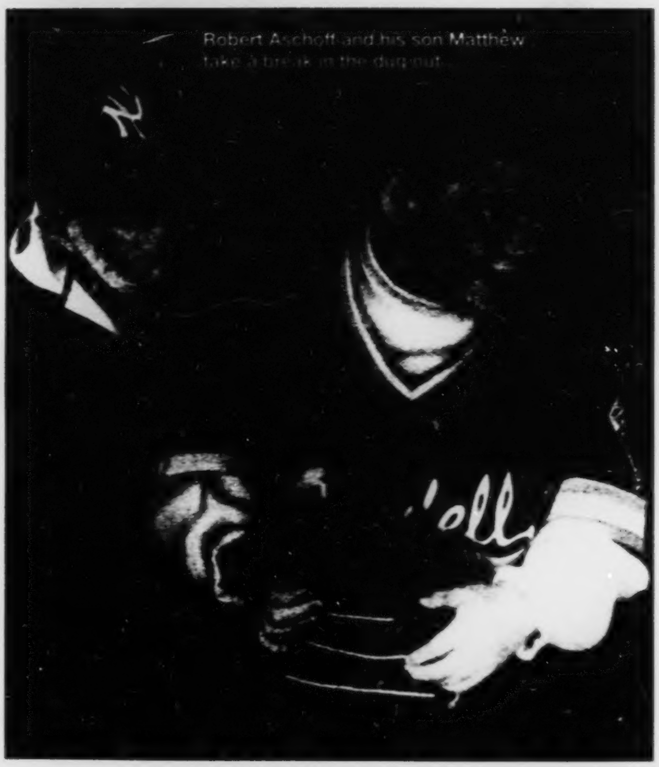
Batter up: Steven Del Greco takes a swing

mainstream activities."

Terri credits the League's rapid expansion mainly to old-fashioned word of mouth. In addition to parents spreading the word, Terri also sends out press releases every year. She leaves flyers at the school's Child Study Team offices in towns that she is targeting and asks the staff to give the information to family's for whom Challenger League would be appropriate.

Fun is the name of the game

Terri sees many benefits for children with special



Robert Aschoff and his son Matthew take a break in the dug out.

needs who participate in Challenger League. "They're getting fresh air, they're getting exercise, and they're getting social opportunity by meeting different children. They are being visible in the community, which is important," she remarks. The children have a chance to have fun with friends and family and

continued on page 50

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Circle #37

Challenger League provides family fun for Joseph Vinci and his son Joe

continued from page 49

"fun is the name of the game. If we're not having a good time, then why are we here?"

Perseverance is also a major ingredient to success. Terri advises, "You cannot give up too soon. You do not know what these kids are capable of. You may have to slug it out for two or more years before it clicks. But when you see them doing it, it is definitely worth it."

Skills, accomplishments, and fun

Baseball teaches many important skills that are useful both on and off the field. The children learn turn taking and following directions, they improve their concentration and focus, as well as learn good sportsmanship. These are all skills that will benefit them in real life situations.

Challenger coach Roger Hoffman notes, "The biggest change that we see in the kids is their enthusiasm for the game as the years go by. When we first started, no one was able to hit the ball, much less field. Today, everyone on the team hits from pitching and we are able to run some simple plays." It is these kind of accomplishments that parents and coaches cherish. Terri's son Stevie has moderate to severe, late onset autism and sensory processing issues. Terri says, "My son has a lot going on. For him to get up there and hit a pitched ball and to run to first base all by himself is a big accomplishment. We are very proud."

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Circle #65

The sense of acceptance and easy-going pace of Challenger League helps everyone have a good time. Flexibility and a sense of humor are a must. Terri recalls a particular game when her son was digging up the bases while out on the field. He dislodged first base and walked off the field with it. Terri recalls with a laugh, "One of the other parents remarked, 'Well, in this league when we talk about stealing bases, we really mean stealing bases!' "

There has been a growth in Challenger Leagues throughout the state. Terri feels that improved communications among the local town's Challenger Leagues has helped. Lou Verile, the founder of the Bergenfield League, was recently appointed to be the New Jersey advisor for Challenger League. Two years ago, he organized a meeting and they decided to have a Fun Day. This proved to be an effective way for the teams to meet each other, to raise awareness in the community, and of course, it would be a fun day for the children. Through the cooperation of all the leagues, who solicited donations from local merchants, Fun Day was a huge success. The children played games and received gifts. As a result, Fun Day has become an annual event and has helped the local Challenger Leagues meet and trade information. Terri says, "There is enormous benefit to the parents because we get to meet and network. We know there is no one book written to tell you where the schools, camps, sports, and programs are. Parents have the knowledge."

Starting a Challenger League

For parents who want to start a Challenger League in their area, Terri advises going to their local Little League and finding out whether there are any Challenger Leagues in their district. If not, parents can start recruiting for their own league at their child's school. Word of mouth is one of the most effective ways to get a message across. It may also be beneficial to enlist the help of some regular Little League members. These baseball veterans can offer help and guidance in coaching a successful team and gaining community support.

Challenger League is a great opportunity for children who have special needs to learn a sport and have some much needed fun. It also offers parents and children a unique bonding experience that they may not have in their day-to-day lives. The benefits to the players are many so why not get out there on the field and batter up! **EP**

Contact the National Little League headquarters for information on specific fees, guidelines, and rules.

For more information on starting a Challenger Division in your area, please contact:
Director of Challenger Division
Little League Baseball Headquarters
PO Box 3485 • Williamsport, PA 17701

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Circle #58

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RECREATION
Sports Play

continued from page 41

"Many of my students require a multisensory approach to learning motor and fitness skills. They benefit from hearing clear and specific directions, seeing a demonstration of new activities, and observing their classmates engaged in an activity, especially if it has multiple directions." He continues, "Many of my students require assistance with moving through the performance criteria that constitute a specific motor skill. Frequently, directions that are broken down into smaller and more manageable increments are helpful."

He gives another example of a boy he has worked with since age 3. The boy has mild cerebral palsy, partial paralysis, and "a great attitude toward movement." Now in first grade, he has no trouble keeping up with his friends. As his friends grow, Passarini will teach him compensation movements so he will still be able to keep up. He makes the environment fun, and his younger students do not even know that they are learning. Says Passarini, "I want children to smile when they see me."

Working on lacrosse skills with Nick Stavropulos.

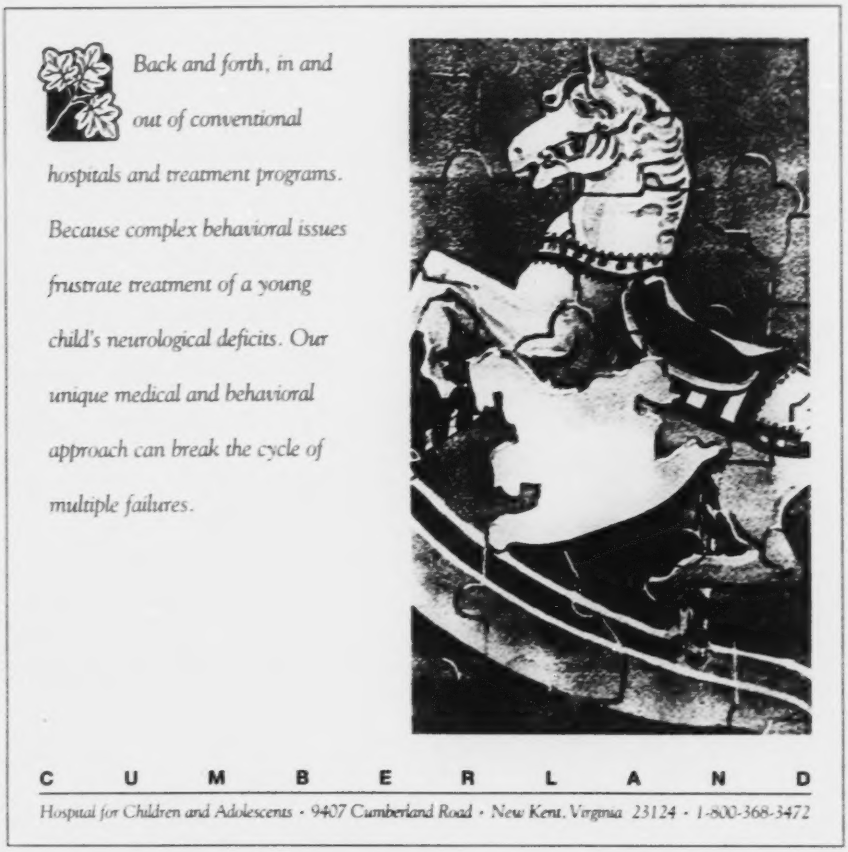
Known by nicknames such as the "Silver Fox" or "Mr. Wizard," after the characters he plays in his classes, John Passarini creates a setting for adapted PE that is both practical and fun. He says that the success of his program comes from the way the curriculum is packaged. "I frequently play the role of antagonist (e.g., the evil Space Blob, Mr. Owl), and the children enjoy developing strategies that will defeat my efforts to win the game. As a player I can control tempo, introduce new skills, and ensure excitement and success. Most of the students leave my class feeling successful, happy, and eager to play with me again."

An example of this type of activity that results from this is "The Blob and the Black Hole," which was created by one of his students. Passarini explains the game: "In this game I was of course designated to be the evil Space Blob that would chase the 'space travelers' (students) with my foam boffer. If anyone stepped on a 'black hole' (rubber mat) he would disappear and have to count to 20 before resuming play. Throw mats were used for 'space pods' (safety zones). Once 'Space pellets' (foam balls) were scattered around the gymnasium, the children had to retrieve them one at a time and return to their spaceship before being tagged and frozen by the Blob. Once tagged, the children had to remain frozen until another space traveler tagged them to set them free."

According to Passarini, this format gave his students the opportunity to "enjoy physical activity, work cooperatively with peers, and feel good about their play experience."

Music is a major component Passarini uses to engage his students. "I play traditional children's music, in addition to rock and roll, country and western, and jazz. Music sets the tempo and mood of the class. I use music to teach listening skills, rhythm, tempo, modulation of movement and movement speed. Music stimulates movement while children practice fundamental locomotor skills."

Passarini also uses PE to help students develop skills that are not necessarily physical in the traditional sense. Andrew Pilkington is in the second grade and has cerebral palsy. Because classmates sometimes have difficulty understanding Andrew's speech, John works with him on communicating during games; for example, helping him to learn how to yell "over here!" during a ball game when Andrew wants the ball thrown to him. Andrew's father, Chris says that incorporating a speech therapy element into a PE environment was a definite plus. He also notes how Passarini use Wayland's annual field day as an opportunity for inclusion.



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"John spends time beforehand, making sure that each event is accessible for every child so they can all participate and compete in some way" says Mr. Pilkington. "If they are unable to compete physically, John gives them some other key role to play. Most importantly, he shares his plan in advance with faculty and staff so there are few surprises and everybody's on the same program throughout the day."

Passarini cannot stress the role of parents enough. "Parents are the first and most important educators a child has. I frequently send instructional sheets home to help parents create a positive movement environment by recreating the class activities." In his opinion, "It is not possible to have optimal adapted PE without good parental rapport."

Diane Love's daughter, Tina is one of John Passarini's students. Now in the eighth grade, Tina, who has Down syndrome, has a positive attitude toward physical education and sports, and participates in a regular PE class. Love credits Passarini for much of Tina's success. She points out that Passarini is also concerned about Tina's future, and is working to help Tina find an activity she really enjoys and will enjoy for her entire life. She describes Passarini in glowing terms, "He is someone who has a gift of total acceptance and unconditional love."

As for teaching children in an adapted PE class, for John Passarini, the main ingredient is trust. Passarini sums it up by saying, "When children believe that an adult enjoys being with them, and cares about their happiness, their minds and hearts open and the learning environment becomes productive." **EP**

To learn more about adapted PE, contact:

The Adapted Physical Activity Council/American Association for Active Lifestyles and Fitness (APAC/AALF), 1900 Association Dr., Reston, VA 20191. Phone: (800) 213-7193 ext. 431; E-mail: webmaster@aahperd.org; Web site: http://www.aahperd.org.

The National Consortium on Physical Education and Recreation for Individuals with Disabilities (NCPERID), 405 Emmet St., Ruffner Hall, Curry School of Education, University of Virginia, Charlottesville, VA 22903; phone: (804) 924-6192.

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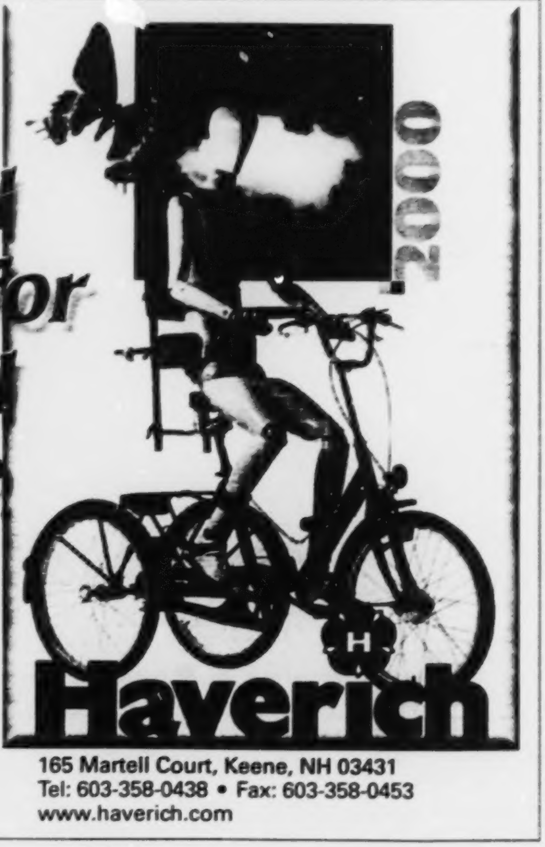

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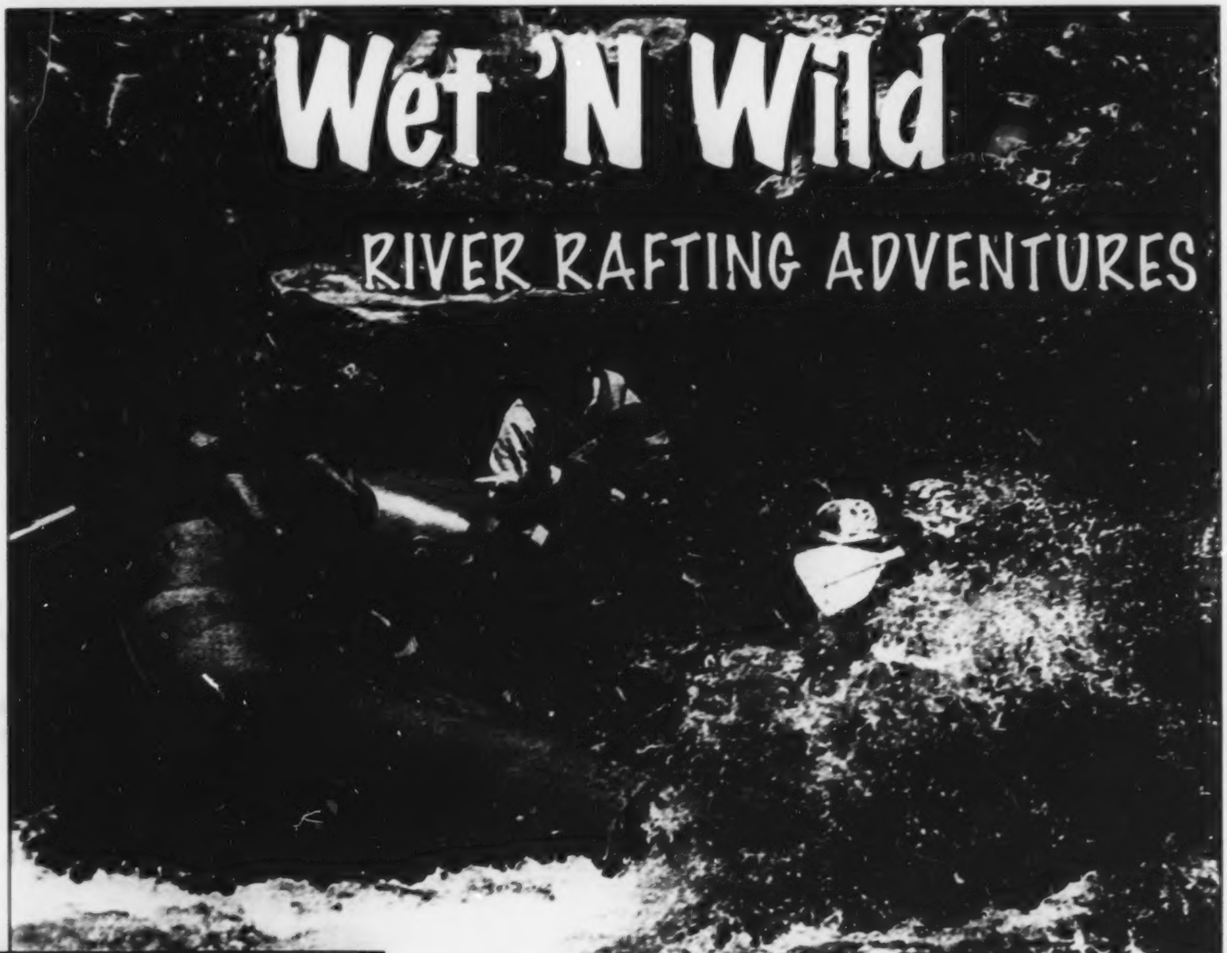
Circle #42

Wet 'N Wild

RIVER RAFTING ADVENTURES



by Ryan Mayo

When it comes to family summer activities, few can compare to whitewater rafting. "It's really a wonderful experience," says Hal O'Leary, river guide and founder of National Sports Center for the Disabled (NSCD) in Winter Park, Colorado. "The charge of hearing the rapids and going through them is very exciting. Rafting is a great way to get outside and involved in a dynamic sport." One of the greatest aspects of whitewater rafting is that it is so versatile. "Unlike some sports, rafting can be enjoyed by the entire family," says O'Leary. The trips are one of the most popular summer programs offered by the NSCD, which has been guiding rafting trips for 20 years .

The Corley-Webster family of Huntsville, Alabama, rafts each summer. Jennifer Corley-Webster and her children, Bobby Corley and Sarah Webster, have truly loved their time out on the water together. Nine-year-old Bobby, who has spina bifida, and 17-year-old Sarah, who has Guillan-Barre syndrome (a neurological syndrome which involves numbness

continued on page 56

Above: Part of the adventure of rafting is getting wet. So be prepared!

Right: All aboard for a wild ride! Seating in rafts can accommodate many different support needs.

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continued from page 54

and muscle weakness in the limbs), have both enjoyed the excitement that the river provides. "It is truly a family adventure, and we have such a wonderful time," she said. "I can't help but laugh at my kids because of the sheer excitement you can see on their faces. That's what it's all about to me."

Adaptations to rafts include using an inflatable mattress for rafters whose bodies are too rigid for seats.

Adaptations on board

Whitewater boats can accommodate people with all types of disabilities. The NSCD primarily uses the 16-foot self-bailing paddle boats. Each of these state-of-the-art boats will hold up to 11 adults. River guide Pat Campanello says the boats can be rigged according to wants and needs of the group. "We allow the rafters the choice of helping to paddle the boat during the trip, or we can put on the oar frame, putting all the work upon the guide for people who just want to ride."

Different adaptations can help rafters with a variety of disabilities enjoy the full river experience. For rafters who need assistance with their balance, handholds can be created inside the raft by fashioning a system of straps on the front and on the sides of the boat for them to hold onto. For safety reasons, no one is ever strapped into the raft.

A raft has large inflated sections called pontoons that cross the middle of the boat. Usually people sit atop these pontoons, but that requires the ability to sit up and balance while the raft is moving down the river. For rafters who need assistance with balance or sitting up, special seats can be fashioned.

One type of seat is a bench which is attached inside the sides of the boat. The seat is tilted slightly so that rafters' backs lean against the pontoon and their knees are elevated. For those who require additional support, nylon camp chairs can be attached to the bench. These chairs have backs and nylon straps on the sides for additional support. Other adaptations include using props to help those who need upper body support. For rafters whose bodies may be too rigid to use seats, guides can even strap an air mattress into the bottom of the boat for them to lie or sit on.

The comfort zone

Most river rafting adventures are offered in either half- or full-day trips. For those who might have difficulty sitting for long periods of time, the shorter trip is probably preferable.

Mary Lou Kulbe of Denver, Colorado, recognizes that her son gets

What to know if you go

Finding a good rafting company is imperative to having a great experience that the whole family will want to repeat. Hal O'Leary points out that it is important to ask questions of any commercial company you choose, especially if it does not have a specialized disabled program available. "Look for their experience with disabilities, that they have certified guides, and good boats and life jackets," O'Leary says. "Definitely ask about the difficulty of the rapids. Anything above a Class III is (becomes) very challenging."

Safety first: Some other tips to remember include checking on safety precautions. It is industry standard and also federal law for commercial river outfitters to use Coast Guard-approved Type-5 personal floatation devices (PFD) or life jackets. Also, every commercial guide is required to be whitewater certified, which also includes certification in CPR and first aid.

Costs: Prices around the country can range up to $100 or more, depending on the time of year and number of rafters on the trip. Aim for discounted rates by putting together your own group of rafters or avoiding the height of the season.

EDITOR'S NOTE:

You can find a river rafting or canoeing company in your area by contacting the American Canoe Association (ACA). They can be reached at:

American Canoe Association
7432 Alban Station Blvd., Ste. B-232
Springfield, VA 22150
Phone: (703) 451-0141 • Fax: (703) 451-2245
E-Mail: aca@acanet.org

tired and hot being out on the water for a long time. Her family has been rafting for the past few years, and they enjoy the half-day trips. Her 12-year-old son Jayce has cerebral palsy and uses a special chair to aid in the enjoyment of the trip. "With Jayce perched up in the middle of the boat, he sees all the interesting wildlife and scenery," she said. "It's such a fun day, and Jayce is just laughing and giggling the whole time."

Rafting is fun for the whole family whether they want to paddle or just sit back and enjoy the ride.

Be prepared for changing weather conditions and getting wet! River guide Hal O'Leary recommends bringing nylon or swimming shorts for their quick-drying ability; two pairs of shoes; a change of clothes; a jacket for the changing weather; and sunscreen, sunglasses, and a peaked cap. Being prepared will make the day much more enjoyable for everyone involved.

River rafting provides an opportunity for the whole family to enjoy the thrills of the outdoors, and though planning is important, enjoying and responding to the spontaneity of nature makes for the most memorable experiences. "It's always a team effort, and everyone learns about themselves and their team members," says guide Pat Campanello. "The day will be full of memories to look back upon forever. Ultimately, people take away the satisfaction of completing such a fun and challenging task." **EP**

Ryan Mayo is the public relations intern at the National Sports Center for the Disabled in Winter Park, CO. For more information, call (970) 726-1540, or visit them on the Web at: http://www.nscd.org.

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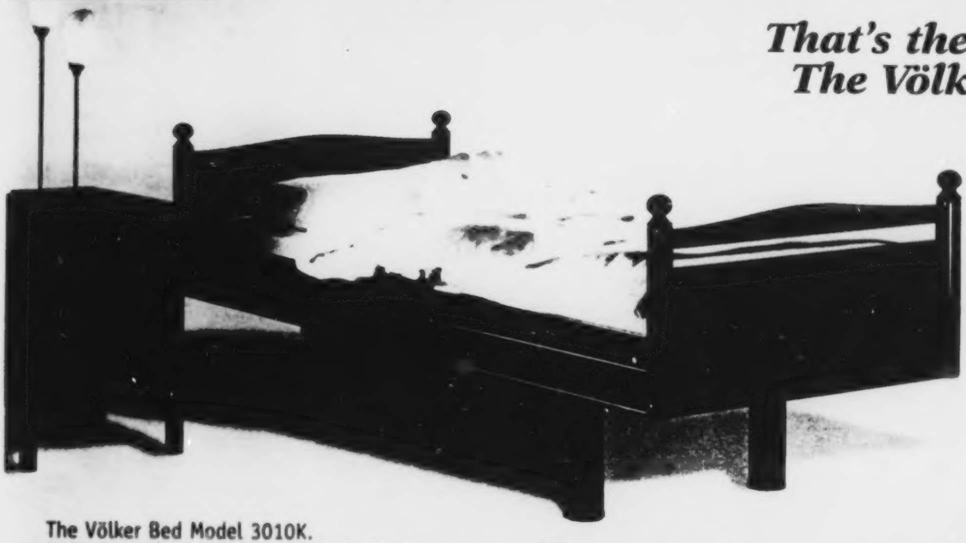

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Circle #43

LEGISLATIVE UPDATE

WHITE HOUSE INITIATIVE ANNOUNCED IN WAKE OF RISING DRUG PRESCRIPTIONS FOR PRESCHOOLERS

In last month's Medical Research Update, EP published the results of a study that indicate a troubling increase in the use of prescription drugs among preschoolers since 1991. In an obvious reaction to the study and to mollify a public uneasy about the study's results, the Clinton Administration has announced the launching of an initiative to reverse this sharp increase.

The drugs in question—Ritalin®, Prozac®, and other potent psychiatric medications, such as methylphenidate and clonidine—are most commonly prescribed to children who are diagnosed with attention deficit hyperactivity disorder (ADHD). However, according to Dr. Laurence L. Greenhill, professor of clinical psychiatry at Columbia University, "Doctors are sometimes too quick to prescribe medications for preschool children. The behavior of an enthusiastic, ebullient 3-year-old with lots of energy can be misinterpreted as attention deficit disorder when it's just a variant of normal behavior." Based on the recommendations of Dr. Greenhill, The National Institute of Mental Health (NIMH) is planning a large-scale study into the safety and efficacy of these medications and their use in treating children under 7 for attention deficit hyperactivity disorder.

Hillary Rodham Clinton, who is championing the White House initiative, expressed her concerns as well, but tempered any would-be all-out attack on the use of the drugs. "We are not here to bash the use of these medications. They have literally been a godsend for countless adults and young people with behavioral and emotional problems." According to a press release from the First Lady's office, the initiative will include "the release of a new, easy to understand fact sheet about treatment of children with emotional and behavioral conditions for parents." In addition, a "national conference on Treatment of Children with Behavioral and Mental Disorders," conducted by the Office of the Surgeon General, the FDA, and the NIMH, is being scheduled for the autumn of 2000.

The maker of the brand-name version of Ritalin, Novartis A.G., acknowledged that the use of the drug had not been approved for children under 6, but that Ritalin has been used safely and effectively in older children for four decades. Nevertheless, they support Dr. Greenhill's proposal for a broad study into the drug's safety and effectiveness in

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Circle #21

preschool children. Eli Lilly & Company, the manufacturer of Prozac, agreed that the controversial over-medication of young children is a "cause for concern." Behavioral therapy, rather, reported a company spokesman, was "often the most appropriate and effective first-line treatment."

GRASSLEY-KENNEDY-JEFFORDS-HARKIN FAMILY OPPORTUNITY ACT OF 2000: A SUMMARY; AND HOW TO ADVOCATE FOR THE ACT

The authors of last year's "Work Incentives Improvement Act," which was successfully passed into law, have united once again in an effort to pass another important piece of legislation, the Family Opportunity Act of 2000. If passed, the bill would provide the following:

- Via a buy-in program, families with a child with a disability will NOT lose their Medicaid coverage for that child if their income surpasses current allowable thresholds. (Lower-income families will be protected by a sliding-scale buy-in plan.)
- Children whose disability is not yet severe enough to qualify them for Medicaid will be able to buy into Medicaid in order to maintain appropriate health coverage.
- States would have the option to allow children with disabilities who receive hospital psychiatric services to receive such services in home or community-based settings.
- Family-to-family information networks, staffed by both parents of children with special needs and professionals, would be created, through which information on technical assistance and available healthcare programs and services could be shared.

Says Senator James Jeffords, "Children without health insurance will now be covered. Those children with disabilities whose health insurance does not cover the services they need will also be covered. Children will no longer be denied healthcare coverage they need, regardless of their family's income."

Advocate for the bill's passage

You can become an advocate for passage of this bill by urging your state senator to co-sponsor the legislation, entitled S. 2274. In addition, you may write a letter on behalf of your family member with a disability or local organization to the leaders of the Senate Finance Committee—Senator William Roth and Senator Daniel Moynihan (contact information below)—asking for their support as well. **EP**

Contact your state representatives and senators at the following Web sites: http://www.house.gov; http://www.senate.gov; or obtain more information by calling the Capitol switchboard: (202) 224-3121.

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Circle #34

590

Tools and Materials that Support the Learning Brain

by Anne Meyer, EdD, and Lucinda M. O'Neill

Rapid advances in science have helped reveal many of the secrets of how our brains work. These new insights have given us new ways to understand individual differences in learning.

We now know that there are three brain systems involved in learning tasks: recognition systems identify patterns, telling us what and where an object is; strategic systems generate patterns, telling us how to do things; and affective systems determine priorities, telling us which objects are important and interesting. Though interconnected, these systems are all unique. Their role in learning, and how they explain variations among learners, guide the Center for Applied Special Technology's (CAST) concept of Universal Design for Learning™ (UDL). UDL is a framework for responding to individual learning differences through the use of technology.

In order to reach learners of varied backgrounds, interests, abilities, and levels of expertise, learning "tools" and materials must be flexible in ways that support the three brain systems involved in learning. Some ways to achieve this include the following approaches:

- Multiple representations of content, providing options to suit various recognition systems.
- Multiple means of expression and control, providing options to support different strategic systems.
- Multiple options for engagement, which act upon the affective systems, providing alternative ways to attract and hold the student's attention and motivating them to learn.

There is always an ongoing search for the right combination of materials that will work, since no single curriculum or software program can provide all of the flexibility needed to create a UDL environment. This requires assembling a variety of tools—computer devices, software programs, materials, and Web sites—that can be used in different combinations for different learners and for different teaching purposes. The flexibility comes in part from the collection itself, which enables varied approaches for reaching a given instructional goal, and in part from the inherent flexibility of each component.

Consider Martin and Euie—two students for whom universally designed tools and materials offer greater access to learning.

Representing content in multiple ways

Martin plays sports, listens to music, and enjoys his friendships. Reading is not the way he commonly gets information or enjoys himself. There are few books in Martin's home. Though smart and curious, Martin has difficulty in school with courses requiring extensive reading. When his class studies the human body, Martin has difficulty grasping the major organ systems and their interrelationships, primarily because this information is being presented exclusively via a printed textbook.

Martin might be able to understand the human body more easily were he able to use a program such as A.D.A.M., the Inside Story (A.D.A.M. Software, Inc.). This CD ROM program presents information in multiple media, including still pictures, animations, speech and text. Unlike Martin's science textbook, where printed words and illustrations are the only alternatives for conveying critical content, programs like A.D.A.M. can use animation to demonstrate relationships, speech to reinforce concepts, and color, sound, and other media to highlight important facts. The essential information is represented in multiple ways.

There is no one way of representing information that is ideal, or even accessible, to all learners. Some students thrive in lectures, others obtain information effectively from text, while still others learn best through visual media such as diagrams, illustrations, charts, or video. One student with a proclivity for art may find an image easier to comprehend than a verbal description; another who is deaf will be shut out completely if only a verbal description is provided.

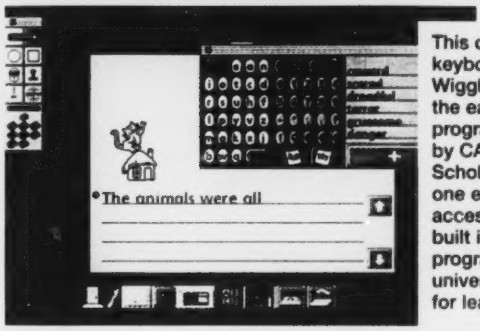
CAST camper Euie Flaherty surfs the Web at home using an adapted joystick

Universally designed materials accommodate this diversity through alternative representations of key information. Students with different preferences and needs can either select the representational medium most suitable for them, or gather information from a variety of representational media simultaneously.

Providing multiple options for expression and control

Euie cannot type a school research paper because he does not have the manual dexterity to use a computer keyboard, but at CAST's summer computer camp, this 16-year-old created a sophisticated multimedia Web page about one of his favorite subjects—science fiction. The page features spinning space ships, the theme from Star Wars, and other dazzling special effects. The World Wide Web offers Euie, whose motor difficulties are caused by cerebral palsy, an exciting new vehicle for learning and self-expression.

For students with physical disabilities there are alternatives that offer support, such as using keyboard commands to replace a mouse or voice recognition software that converts speech into text. However, these physical adaptations are only a small piece of the adjustability needed for different strategic systems. Each step in learning a new skill needs to reflect the individual learner. This is best accomplished by "apprenticeship" learning, a teaching approach which allows students to learn from successful examples; provides support at different skill levels; provides ample opportunities to practice skills; provides "feedback," or information, on whether the answer is right or wrong so the learner can monitor his or her own progress; and provides opportunities to demonstrate skills.


The animals were all

This on-screen keyboard in WiggleWorks®, the early literacy program developed by CAST and Scholastic Inc., is one example of accessibility features built into software programs that are universally designed for learning.

A number of educational software programs allow practice to be customized to offer different levels of support and difficulty. With Access to Math (a software program by Don Johnston, Inc.), teachers can create a worksheet and adjust the program to alert the student to any mistakes as he or she is working on a problem. This enables the student to make corrections along the way. Alternatively, the program is flexible enough to be set to provide feedback on demand. When the student clicks on the feedback button after completing one or more problems, the program provides feedback in visual and auditory formats. This immediate feedback helps students

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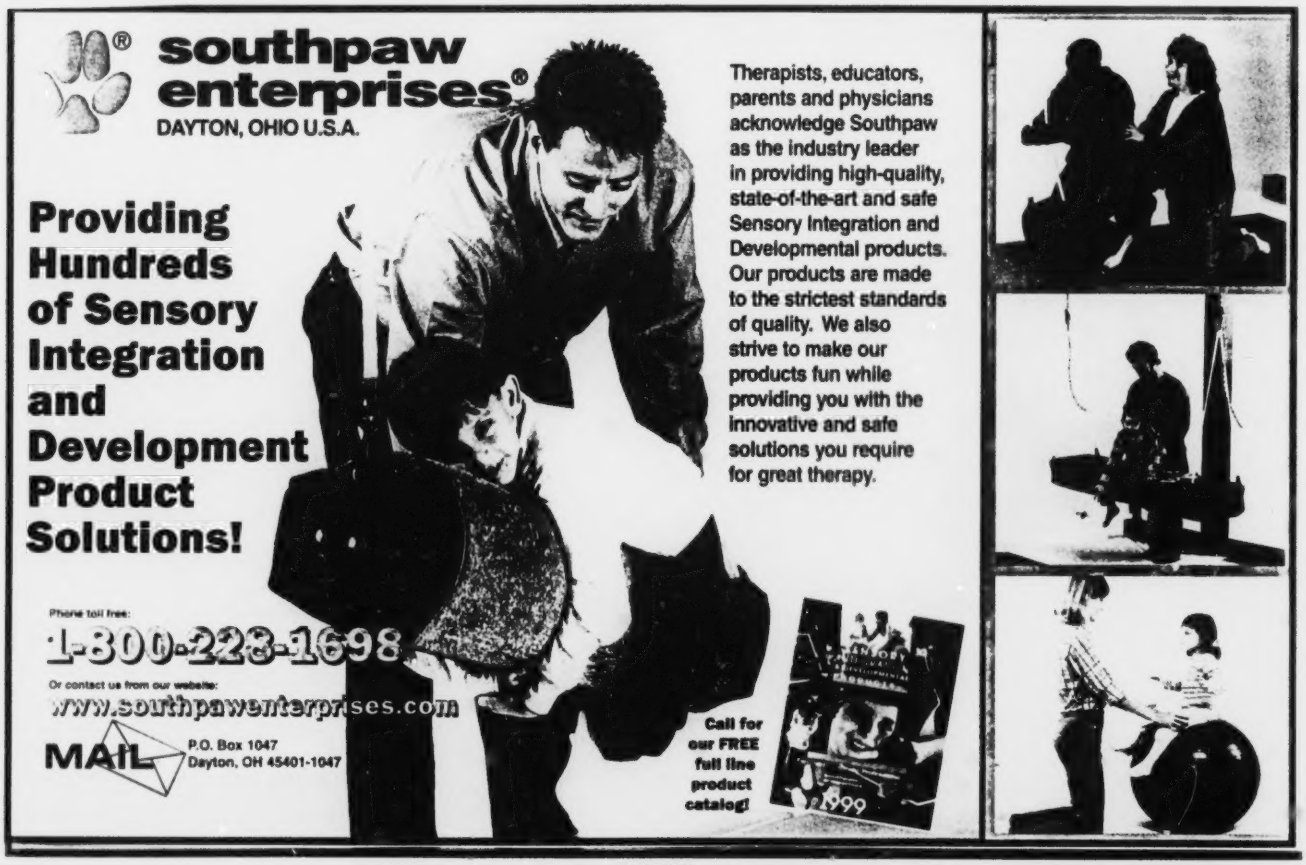
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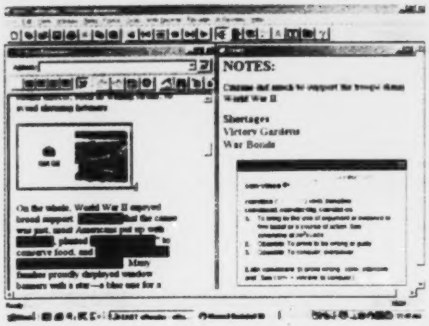

NOTES:

Shortages
Victory Gardens
War Bonds

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continued from page 61

analyze their work, both improving their performance and helping them learn self-monitoring skills.

Educational research indicates that more options for expression, including artwork, photography, drama, music, animation and video, open doors for a greater number of students to successfully communicate ideas, knowledge gained, and talents. This applies to students with particular skills and proclivities as well as to students with disabilities that prevent them from using certain media effectively or at all.

A composition tool that offers digital recording and playback enables students to compose ideas orally, then analyze and revise them until they "sound right" before writing. Drawing and other graphics tools can help students generate ideas and organize their work visually. For teachers, providing multiple options for expression requires thinking carefully about the purpose of an assignment. Requiring that a student "write a story" limits the student's options to text. However, requiring that a student "create a narrative" can open opportunities for a variety of modes of expression. Providing multiple approaches through multiple media allows students a greater opportunity for successful learning, and then builds momentum.

Motivating children to learn

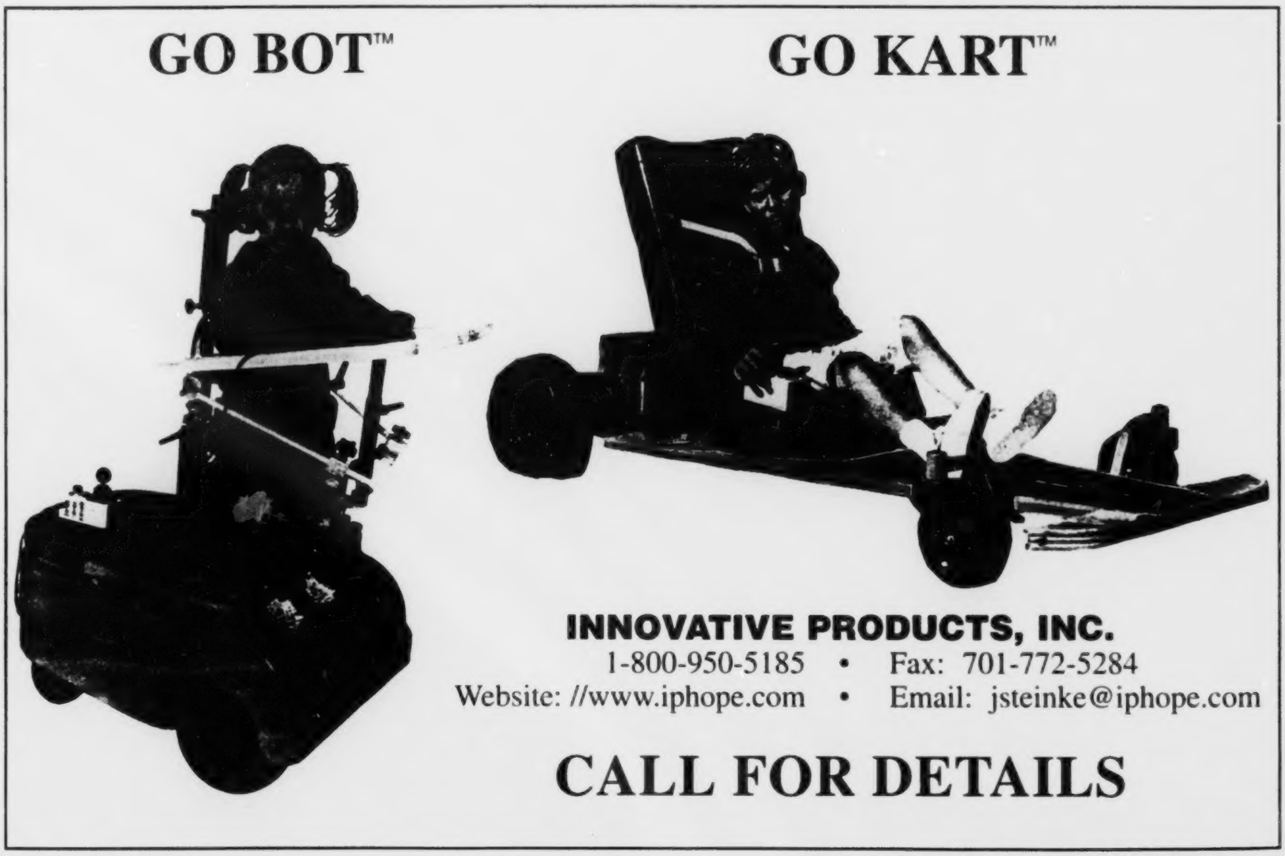
Engaging children in learning includes building their confidence and arousing their interest, enthusiasm and desire to learn. Motivating children to learn may be the most challenging aspect of teaching and instructional design. Next month, we will explore ways in which universally designed tools and materials can support the learning brain's affective systems, where engagement and motivation are generated. **EP**

Anne Meyer, EdD, is co-executive director of CAST, the not-for-profit Center for Applied Special Technology, in Peabody, MA. Lucinda M. O'Neill is a staff writer at CAST.

RESOURCES

A.D.A.M., the Inside Story, is available at http://www.adam.com.

Access to Math is available at Don Johnston, Inc., 26799 West Commerce Drive, Volo, IL 60073 USA, (847) 740-0749; http://www.donjohnston.com.



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Circle #45

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Assistive Technology 101

Part 2 Accessing the Computer

by R.J. Cooper

Last month, Assistive Technology 101 looked at choosing a computer system to meet a user's special needs. This article examines specific adaptations which allow a person with special needs maximum access to a computer system.

Above left: Buddy Button switches by TASH Inc. Above: Big Red switch by Ablenet, Inc.

What are the basic and necessary hardware and/or software to set up a computer system for a user who has special needs? Just as there is no specific type of computer for people with disabilities, there is no single correct answer to this question. Since the needs of each user are unique, those needs must be analyzed so appropriate computer hardware and software can be identified and installed.

Begin by "breaking down" the needs into "access" or "instructional." (This article will discuss access needs.) Simply put, having an access need means that the computer requires some adaptation in order for your child to use the computer, software programs, and the Internet.

Traditional methods of accessing a computer are with a keyboard and mouse. However, if a child with a disability has difficulty using these methods, there are many different adaptive devices and software which can replace them.

If the user has profound physical disabilities, there is a chance he or she will need to use a switch in order to interact with the computer. Users who can only rotate their heads slightly to push against and activate a single switch can independently surf the Internet using Netscape™ Communicator, or any other "point and click software." Point and click software allows the user to move the cursor to the desired location on the computer screen to "click" on his or her choice. A software program and/or hardware (a switch) that permits alternative access to mouse functions is called a "mouse emulator." A mouse emulator is a device (and all its connections) that takes the place of and functions as a regular mouse. (Questions about single switches—and how to connect them—are among the most common I receive. This installment will cover "single switch mouse emulators." Other mouse emulators, which are faster, will be addressed in a future installment and include joysticks, trackballs, and infrared head-reflecting mouse emulators.)

"Switch" on your computer

A switch is a simple on/off device that stays on only for the time the user is activating it. There are hundreds of switches available, from small, 2-inch round ones to infrared eye-blink switches (by Word Plus). My favorites are the Buddy Buttons and Big Buddies (by TASH, Inc.). Ablenet, Inc., makes the popular Big Red and Jelly Bean® switches. Switches for users with many types of disabilities, from mild to severe, are available. Believe it or not, one simple switch, controlled by someone raising his or her eyebrow, or moving a toe, *can* control a computer. However, in order to use a switch, you must also have a switch interface (connection).

A switch interface is a device that allows the switch to be plugged into the computer. It works in conjunction with single-switch, mouse-emulation software. Don Johnston, Inc., makes a Mac or PC switch interface, as do several other companies.

Simply plugging in a switch through a switch interface can allow almost

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What is assistive technology, or AT?

It is any device or adaptation that helps a person function in his or her daily life. The IDEA '97, (Individuals with Disabilities Education Act) defines AT as "any item, piece of equipment, or product system...that is used to increase, maintain, or improve functional capabilities of a child with a disability." This article refers to AT as it relates to electronic devices: usually computers, communication devices, and software programs.

Resources

SWITCHES

Buddy Buttons & Big Buddies by TASH, Inc.:
http://www.tashint.com
Big Red & Jelly Bean® by Ablenet, Inc.:
http://www.ablenetinc.com

SWITCH INTERFACES

Don Johnston, Inc.: http://www.donjohnston.com

MOUSE EMULATOR SOFTWARE

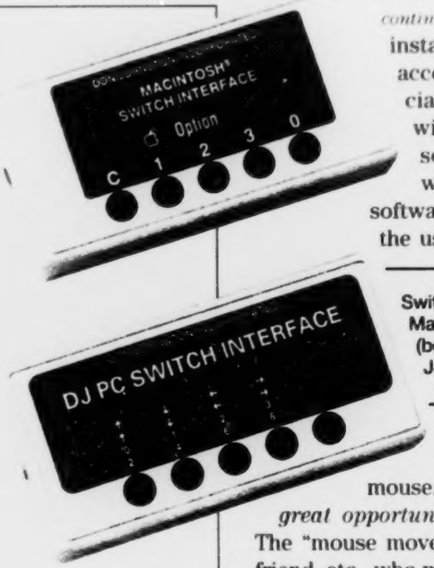
ATCenter: http://www.at-center.com
Intellitools' Clickit®: http://www.intellitools.com

POSITIONING ARMS

Magic Arm by Enabling Devices:
http://www.enablingdevices.com
Universal Mount by Don Johnston, Inc. & Ablenet, Inc.

OTHER RESOURCES

Alliance for Technology Access: http://www.ataccess.org



Switch interfaces: For Macintosh (top) and PC (bottom), both by Don Johnston, Inc.

continued from page 63

instant, but limited, access to most commercial software, even without "access" software. However, when single-switch software is not available, the user will also require another person to help by moving the mouse. **This can be a great opportunity for interaction.* The "mouse mover" can be a sibling, friend, etc., who moves the mouse and positions the cursor. The switch user can then click with the switch. Through this method, all point and click computer functions become accessible for the switch user, with the added benefit of social interaction between the user and the helper. If your mouse mover is young (I find age 5 to be a minimum), then all you need to do is keep him or her from clicking, to allow your switch user time to do the clicking with his or her switch. Games are great in this manner.

Mouse and keyboard emulator software

Mouse emulator software "sandwiches" itself in between the operating system and the application, so that the application "thinks" someone is moving and clicking the mouse. An example of such software is Clickit®, which can be found on the IntelliTools Web site. With this software, which runs parallel with existing software games or applications, a display of red circles appears on the screen. Clickit® highlights these circles, called "hotspots," one at a time until the user clicks the switch to indicate his or her choice. The chosen item's function is then executed. This method is a bit slower than traditional mouse pointing, but for some, it is a true blessing.

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Circle #40

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There are many other mouse emulators available and many sources that offer them. ATCenter (http:// www.at-center.com) lists quite a bit of inexpensive assistive technology. Another source is Alliance for Technology Access. This nonprofit group and nationwide network helps children and adults with disabilities gain access to adaptive technology through community-based centers and provides consultations, product demonstrations, makes referrals, and presents workshops on technology use.

Keyboard emulator hardware and/or software "tricks" the computer into thinking the user is typing on a regular keyboard, even though an on-screen keyboard emulator is being used. With these hardware devices and software programs, any operation can be carried out, whether it is word processing or e-mail.

Positioning your switch

Once the proper switch has been selected, auxiliary devices, such as a positioning arm, can allow even more tailored access to the computer. A positioning arm is a piece of equipment that allows the switch to be positioned to suit the user. This metal device, which consists of a "shoulder," "elbow," and "wrist" joint, can be moved easily into any one of a thousand positions. Switches can be attached at the "wrist;" the "shoulder" clamps to a desk or wheelchair. The Magic Arm, by Enabling Devices, is a positioning arm with a knob at its "elbow" to tighten and loosen all three joints. Ablenet, Inc., and Don Johnston, Inc., make a positioning arm called the Universal Mount. It is similar to the Magic Arm but it has a spring-loaded lever at the "elbow" instead. **EP**

RJ Cooper holds a BA in developmental psychology and has been working with, and developing, technology materials for people with special needs for over 16 years. He is the founder and president of RJ Cooper and Associates, which develops and sells their own assistive technology hardware and software programs. http://www.rjcooper.com.

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Circle #46

Part 4

INDIVIDUALS WHO USE AUGMENTATIVE AND ALTERNATIVE COMMUNICATION SPEAK OUT

by Peggi McNairn, PhD, CCC/SLP, ATP, and Cindy Shioleno, MEd

The first three parts of this series have focused on parents' perspectives on AAC. In this final installment, however, people who use AAC devices share their thoughts and experiences so that parents and professionals may learn from them.—The Editors

ean Marie Quirk, 32, of Ft. Worth, Texas, is the youngest of four children and has cerebral palsy. She is unable to walk, talk, or even sit without assistance. "When I was born, the doctors told my parents not to expect too much from me because I had cerebral palsy," Jean Marie remembers. "They even told my parents that they should just put me in an institution and get on with their lives!"

Instead, Jean Marie's parents took her home. Among the other challenges they had to meet, Jean Marie and her parents had to negotiate the world of assistive technology and augmentative and alternative communication devices. Today, Jean Marie communicates using a laptop computer with special communication software. She has graduated from high school and moved out into a home of her own. "I wish those doctors could see me now!" beams Jean Marie.

Augmentative and alternative communication (AAC) is not familiar to most families. Parents are sometimes left to persevere on their own to find a communication method for their child, just as Jean Marie's parents had to. Five individuals who use AAC and one parent of a child who uses AAC have shared their personal experiences and opinions so that other AAC users, parents, professionals, and manufacturers can learn from them.

What I wish my parents had known about AAC

According to the American Speech-Language-Hearing Association (ASHA) in Rockville, Maryland, augmentative and alternative communication "refers to all communication that supplements or augments speech." AAC covers a broad range of techniques and strategies, from simple picture boards to sophisticated, computer-based communication devices with synthetic voices. Other examples of augmentative and alternative communication may include facial expressions, gestures, body postures, eye-gaze, sign language, drawing, and writing.

For Randy Hastings of Texarkana, Texas, AAC was initially a paperboard with pictures drawn on it. "I was born with cerebral palsy seventeen years before the Individuals with Disabilities Education Act (IDEA) was passed. Because I couldn't talk, I wasn't allowed to attend public school. Instead, I attended a special treatment center from the age of 6 until I was 16," recalls Randy. "After IDEA was passed in 1975, I finally entered the public schools. I was given a headpointer that I wore like a

Heather uses her device to access her computer to do school work, as well as to communicate with friends.

Above: Daniel (right) and his brother Andrew get some fresh air in their back yard. Below: Daniel started using AAC devices at a young age.

baseball cap and a manual communication board with Bliss symbols *(Editor's Note: Bliss symbols, or Blissymbolics, use graphic symbols, many of which are geometrical shapes and lines, which can be combined in sequences to depict meaning.)* My parents spent hours teaching me how to point to those symbols to say what I wanted to say."

Jon Feucht of Whitewater, Wisconsin, had a similar introduction to AAC. "Prior to the time that I was 20, I used a word board which I had to have people read over my shoulder as I pointed to each word."

Fortunately for Randy and Jon, their parents did not stop searching for a better communication system. "What I think parents need to know is to never give up on trying to find the perfect communication system for their child," says Jon. "I tried almost every communication system on the market and nothing worked. I almost gave up before discovering the right device. It took me 20 years to find mine, but I now can use it for the rest of my life."

Seventeen-year-old Daniel Klauditz of Toms River, New Jersey, also cautions parents to look at everything that might affect their child's communication, and that includes positioning. Daniel, who has cerebral palsy, spends most of his day in a wheelchair. "I cannot begin to describe how disappointed I am with my wheelchair," says Daniel. "Having a bad chair makes it really difficult to use my communication device as well as I can. Unfortunately, I don't think anyone understands this."

In spite of the challenges the children and their families must overcome, parents can maintain high expectations for their children. "I am a 22-year-old college student from the University of Wisconsin-Whitewater, double majoring in English and psychology. I also hope to get my masters in Special Education," says Jon. "I have my own apartment and live by myself. All these things sound like any successful person; however, I have cerebral palsy and can't walk or talk."

Tracy Rackensperger of Altamonte Springs, Florida, provides another example of how using AAC should not be a barrier to success. "I have cerebral palsy and use assistive technology and augmentative communication. I graduated from the University of Central Florida with a BA in Radio-Television. I am going to try to get into graduate school and get my MA in communication. My long-term goal is to get a doctoral degree in Communications."

In addition to going to school, Jon and Tracy are both young entrepreneurs. "I'm also starting a camp for children with disabilities so they won't need to go through the hardships like I did, not being able to communicate well," reports Jon. Tracy has also decided to act as a role model for others. She says, "I am starting a small business designed to educate people about augmentative communication and assistive technology."

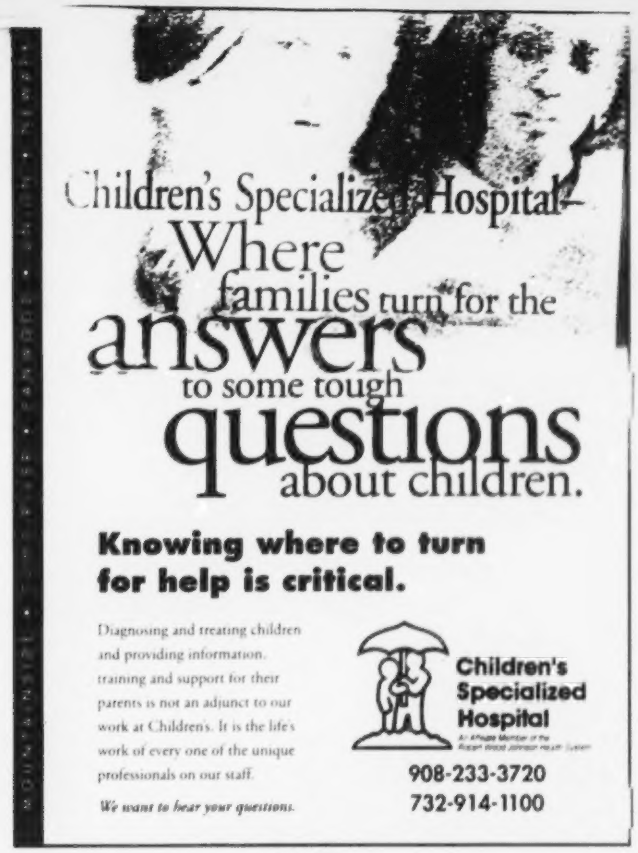
What I wish manufacturers knew about AAC

The field of AAC has seen an explosion of devices in the past twenty years. Even though there are over 200 different AAC devices on the market today, there are many features of this new technology that continue to need refining. "I wish AAC device manufacturers would find an easier way for me to access my computer's software using my device," says Heather Hartman of Arlington, Texas. "I'd like to be able to just play games as well as do my school work."

Daniel's wishes are more personal. "I would like to have a key to lock my device to stop people from messing with it," says Daniel. "I also want my speech to sound more like a real voice."

A common problem that many device users experience is glare from overhead lights or the sun. "One thing I hadn't thought of and no one brought to my attention was the fact that with a

continued on page 68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dynamic display device, like mine, you can't see to use it outdoors," says Tracy. Although Daniel does not use a dynamic display device, he experiences similar problems. "I wish the lights on my device could be changed," notes Daniel. "I can't see them when I am outside in the sun."

What I wish I had known about AAC

The importance of early intervention is not lost on individuals who rely on AAC for communication. "I wish I had known about AAC at the beginning of my school years," says 18-year-old Heather Hartman, who has cerebral palsy. Heather attends tenth grade at Lamar High School in Arlington, Texas. "Now that I have a device, I can communicate with my friends. I also feel more like I am a part of the class."

Unlike Heather, Daniel was exposed to AAC at an early age thanks to the efforts of his parents. However, finding knowledgeable professionals and successful AAC role models has proven to be an ongoing challenge. "I wish I had known some people who could help me when I first started using AAC," says Daniel.

What I wish professionals knew about AAC

The individuals interviewed stressed the importance of successful role models who use AAC. Laura Warburg of Louisville, Kentucky, mother of 10-year-old Candice, agrees. Candice has cerebral palsy and has overcome many obstacles in her short lifetime. Laura reflects, "We would have gained so much in those early days, and even today, from one-on-one mentoring of a family with a child with similar abilities and needs." Jon Feucht agrees, pointing out the need for professionals to connect families: "Professionals need to look for other AAC device users because families with a child with a disability may never have seen or heard of AAC."

The need for specialized skills and training is also important for any professional working with students who use AAC. As important as AAC role models are in the intervention process, professionals must also become knowledgeable about their students'

About the people interviewed:

Jon Feucht lives in Whitewater, Wisconsin. He can be reached at WateryJon@aol.com.

Heather Hartman lives in Arlington, Texas, with her parents, sister Alcia, and brother Paul.

Randy Hastings lives in Texarkana, Texas, with his parents.

Daniel Klauditz lives in Toms River, New Jersey, with his parents and brother Andrew.

Jean Marie Quirk lives in Ft. Worth, Texas.

Tracy Rackensperger lives in Altamonte Springs, Florida. She can be reached at tdoggog@aol.com.

Frank and Laura Warburg live in Louisville, KY, with their 10-year-old daughter Candice, and 6-year-old son Joey.

> "SOME OF US HAVE SO MUCH LOCKED UP INSIDE AND ARE SO FRUSTRATED BECAUSE YOU DON'T UNDERSTAND OUR NEEDS."

devices. "I wish professionals and teachers would learn how to use my communication device," says Heather. The teen participates in a fully inclusive educational program, and has had the difficult task of training her new teachers each year. "I just wish they would all take the time to learn my device and to work with me on it," reflects Heather.

Because of the nature of their disability, many individuals who rely on AAC require special adaptations for academic and intellectual testing. Failure to provide appropriate adaptations may result in test scores that reflect an individual's physical disabilities rather than his or her intellectual abilities and skills. "Most professionals have given me tests that simply make me look bad," says Daniel.

Randy empathizes with Daniel's feelings. "Appearance can be so deceiving," he says. "I lived for thirty-four years in frustrating, angry silence before someone gave me a device with a voice and the training on how to use that device. So, experts, please don't pre-judge a nonverbal, handicapped person as mentally retarded. Some of us have so much locked up inside and are so frustrated because you don't understand our needs."

Though there are many devices available today, parents must still advocate for their children to make sure they have the right one(s). Much progress has been made, but there is still much left to do. **EP**

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The authors welcome questions and comments.

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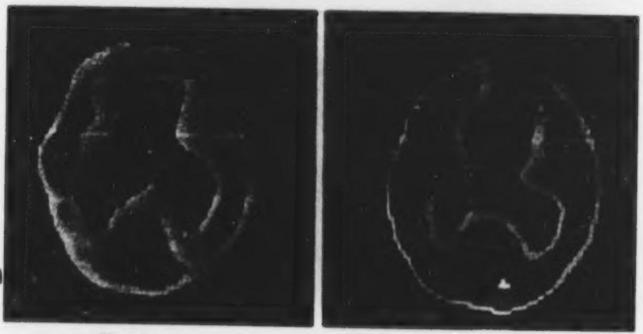

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Circle #62

UNIVERSITY AFFILIATED PROGRAMS

Research to Practice on Issues of Disability

by David Mank, PhD

An infant with Down syndrome and his parents get guidance on how to promote language development; a school-aged child is taught how to use a new augmentative communication system; a teenager with autism prepares to enter the work force; parents of children with a wide range of disabilities meet to discuss legislation in their state and to share mutual support and information; aging parents of adult children with disabilities learn of housing options and available community supports; parents, teachers, medical, and health-related personnel get training on the latest of what science has to offer in the practice of supporting and assisting people with disabilities.

These are scenarios that are repeated hundreds of times daily across the country through a network of interdisciplinary research, training, and service development centers called University Affiliated Programs (UAPs). UAPs are so named because they are affiliated with major universities. UAP Centers are in every state and territory in the United States—61 in all. Authorized by The Developmental Disabilities Assistance and Bill of Rights Act (PL 104 – 183) (DD Act), UAPs have been making a direct and specific difference in the lives of people with developmental and other disabilities, their families, and their communities, for nearly 40 years.

Within their states and territories, and as an Association (The American Association of University Affiliated Programs), UAPs are working to accomplish the major goals of the DD Act: independence, productivity, and community inclusion for people with disabilities. The UAPs help make community participation possible for people with disabilities through research, training of service providers, and bringing advances in science into everyday practices. This unique, collaborative network is interdisciplinary, which enables it to deal with issues across the spectrum of disabilities and throughout the life span.

A successful, quality life in the community for children with disabilities starts with well-trained support personnel.

The DD Act continues to meet a significant societal need today as new research, policies, and attitudes evolve to include and support individuals with disabilities in the mainstream of American society. Through the passage of the Americans with Disabilities Act, the Individuals with Disabilities Education Act, the Technology-Related Assistance for Individuals with Disabilities Act, the recent Ticket to Work and Work Incentives Improvement Act, and other broad-reaching legislation, people with disabilities have made great strides toward independence, productivity, and inclusion. However, these ideals have not yet become a reality for many people with disabilities. UAPs work as partners with federal, state, and local leaders to bridge the gap.

From theory to action

By working from concept to consumer, UAPs endeavor to translate and put into practice the best of what science has to offer. Each UAP is housed within a university and is mandated to work in and with the communities where they are located. This gives UAPs the opportunity to bring the best interventions in support and care for people with disabilities into community practice. UAPs accomplish this mission through the following components:

- *Research and dissemination of information.* Findings from UAP research as well as research conducted at other universities is used to better understand and guide policy and practice at the local, state, and federal agency levels. The results are increased effectiveness and speedier conversion of research initiatives into implementation. UAPs also collect information and

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measure outcomes relative to our nation's success at providing care for citizens with developmental disabilities. Governors and state legislators use these data as a guide to create and implement policy.

- *Emerging trends and issues.* UAPs are also engaged in work that links disability issues and broader community issues, such as managed care; welfare reform; changes in social security; the aging of baby boomers; affordable housing; use of new information technologies; transportation; at risk children; violence and school discipline; and ethical issues. These are some of the social and community issues that have an impact on the lives of people with disabilities now and in the future. UAPs are working to incorporate disability issues into community development efforts.
- *Preparing personnel for the future: preservice training.* A successful, quality life in the community for individuals with developmental disabilities begins with well-trained professionals and support personnel. Each year, more than 5,000 long term and 60,000 short term trainees receive the most up-to-date information, practice their skills under the mentorship of experienced faculty from a range of academic and clinical departments, and work in real world community and family settings.
- *Direct services and supports.* UAPs use their core funding to leverage additional local, state and federal resources to provide quality, exemplary services directly to community agencies, families and individuals. These include a broad array of services based on local needs of individuals and their families, including personal assistance, clinical, health, prevention, early intervention, education, and vocational services, direct-service staff training, diagnostic services, supported employment, assistive technology and person-centered planning. The UAP system is designed to be flexible and able to respond to the changing needs of the communities and the state that it serves.
- *Technical assistance.* For many UAPs, it is the technical assistance, rather than direct services, that has the greatest impact on the ability of state and local service-delivery systems to adequately meet the needs of people with developmental disabilities. Technical assistance is provided to schools to devise the best ways to include children with disabilities in regular classrooms; to employers to hire people with disabilities; to community housing authorities for community participation of people with disabilities; and to community and state agencies who support people with disabilities.

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AAUAP has joined forces with The International Association for the Scientific Study of Intellectual Disabilities (IASSID) as co-hosts of the IASSID Conference to be held in Seattle, Washington—August 1-6, 2000. This Conference offers a unique opportunity for researchers, parents, consumers, and professionals to interact with an international audience. Sessions will highlight developments occurring around the world, not only in the United States. AAUAP will host a number of sessions, including a poster session and reception, that will highlight projects from UAPs across the country.

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For more information on the UAPs, the AAUAP, or the international conference please visit our Web site at: http://www.aauap.org; or contact the AAUAP Executive Director, George Jesien, PhD, at (301) 588-8252; 8630 Fenton Street, Silver Spring, MD 20910. **EP**

David Mank, PhD, is President of AAUAP and Director of the Indiana Institute for Disability and Community (UAP). He is also a professor at Indiana University.

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Keeping the Spirit Alive

Web sites that support children with disabilities in their pursuit of healthy minds and bodies

by Vanessa B. Ira

Every now and then, EXCEPTIONAL PARENT receives e-mail messages from readers alerting us to some Web sites that might be useful to either parents or their children with special healthcare needs. The theme of this month's issue is sports and recreation, and we have chosen to feature (below) three sites that help support pursuits promoting healthy spirits, minds and bodies.

Disabled Sports USA (http://www.dsusa.org)

This is the well-designed Web site of Disabled Sports USA, a nonprofit organization started in 1967 that provides national sports rehabilitation programs to anyone with a permanent physical disability. The site is packed with useful information in various areas, including a month-by-month "Schedule of Events" and "Athlete Highlight," which profiles an athlete with a disability. This month, the site features Roderick Green, the young basketball star who had the lower half of one of his legs amputated. Most notable in this site is its user-friendly and detailed "Disability Related Sports & Recreation Links."

Shake-a-leg, Inc. (http://www.shakealeg.org)

Shake-a-leg, Inc., a nonprofit organization, provides support to people who have experienced physical trauma, with an emphasis placed on spinal-cord and related nervous-system impairments. This Rhode Island-based group seeks to serve people through its "multi-faceted therapy programs that focus on improving the mind, body and spirit." Shake-a-leg's Web site provides users with a way to keep up with the organization's activities detailed in its "Events" section, and contains a list of its many "Programs," such as "Confidence is Cool Youth Program;" "Adaptive Sailing Program;" and "Body Awareness Therapy Program for Teenagers."

Special Olympics (http://www.specialolympics.org)

The site is loaded with information, such as how to get involved with the Special Olympics, program locations, and a calendar of games and competitions. It also includes some outstanding channels and features. For example, "Sport," which gives users the option to find out more about any of the sports offered by the Special Olympics, includes Coaching Tips, Athlete Tips, and links to sites related to particular sports. By clicking on "Meet Special Olympics Athletes," users can read individual profiles about athletes all over the globe and see Web pages created by athletes who participated in the 1999 World Summer Games. There is also a "Shop online" option where users can shop on some of the most popular online merchant sites, from which 15 percent of every purchase is donated to Special Olympics.

United States Cerebral Palsy Athletic Association USCPAA (http://www.uscpaa.org)

The nonprofit USCPAA has resource centers in over 40 states across the country where athletes with special needs can turn to for assistance and support in coordinating their training and sponsorships. USCPAA.org contains all the basic information on the organization, such as its mission, whom to contact, and a section on "News" and "Upcoming Events" in various sports (track and field, soccer, swimming, and more). **EP**

E-mail your comments on this article, or other ideas or suggestions for EParent.com, to: Vanessa B. Ira, Internet Projects Advisor and Consultant, at: vira@eparent.com. Or call (201) 634-6550 ext. 213.

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608

ASK THE DOCTOR

To Medicate or Not to Medicate: That Is the Question.

Daniel B. Kessler, MD, FAAP

We live in pretty remarkable times. The mysteries of the brain, the most complex "machine" ever seen, are slowly unfolding. In the process, the stigma attached to problems of behavior and emotional well-being is slowly falling away. However, we still have a long way to go in making the necessary resources available to help children with these problems.

There is no "parity" between medical and behavioral health. Insurance benefits, for those lucky enough to have them, will likely cover an appendectomy much more readily than behavioral counseling. Finally, though, we are beginning to understand that problems of the brain do not carry a stigma, nor do they indicate any more about our moral fiber and character than problems of our kidneys or blood cells. We are not "evil" (a concept held over from the Middle Ages), or "bad" if we have problems regulating our thoughts or worries.

There is no reason for children to suffer from the problems of disordered behavioral control, anxiety, or panic any more than adults should. Today, we have at our disposal an array of interventions, both medical and psychological, to help children and their families. It's about time.

Making the decision to medicate

Despite rapid advances, the decision to use these interventions in the treatment of problems of behavior and emotional well-being still rests with the family. You cannot be forced to medicate your child because he or she is having emotional problems. Parents should make these choices knowing the facts, not the fallacies, of medical intervention. There is a multitude of resources readily available to provide families with these facts. These resources range from professional academies to governmental agencies and support organizations. They can be accessed with just a telephone call or mouse click, or through a visit to your local library, parent resource center, or parent-to-parent group. (See the Resources section for specific organizations and contact information.)

Throughout the decision-making process, your child's primary medical provider should assist you and answer your questions. If he or she cannot, then they should help you locate someone who can. If they are unwilling to help, then you should fire him or her and find someone who will. That may sound harsh, but I believe it is necessary; these decisions are too important not to be given immediate attention.

In the meantime, I will address a few of the most common questions that parents have about the use of medications for the treatment of behavior and mood in children. This article should not replace the advice and recommendations of your child's primary medical provider. Decisions to stop or start a medication should always be checked with him or her first.

Q Why is my child's doctor prescribing the same medication for my child that I take for high blood pressure?

A While we develop medications for specific purposes, we frequently find out (quite by accident sometimes) that they have uses beyond that for which they were originally developed. Thus medications that were originally developed to treat high blood pressure (clonidine or Guanfacine), for example, are now commonly used to control anxiety or tics (involuntary motor movements). Even though they help your child control the behavior, they do not address the underlying cause of the behavior. When the medication wears off, the behavior or difficulty may return.

Q Why does the doctor keep changing my child's medication?

A Although much is known about the use of medications to treat behavioral and emotional difficulty, each individual situation may involve some degree of trial and error. For example, if one antidepressant or stimulant fails to help a certain symptom such as depression or hyperactivity, that is

---

Ask the Doctor addresses issues of concern to our readers and is usually coordinated on a monthly basis by David Hirsch, M.D., a pediatrician and member of *Exceptional Parent's* Editorial Advisory Board. Dr. Hirsch is a partner in Phoenix Pediatrics, Ltd., in Phoenix, Arizona, and specializes in treating children who have developmental disabilities and chronic illnesses.

Parents should review any suggestions made in this column with the appropriate professionals. Mention of specific products or medications illustrate suggestions and are not endorsements of any specific products.

Send questions to: **Ask the Doctor,** *Exceptional Parent*, 555 Kinderkamack Road, Oradell, NJ 07649-1517, or fax, (201) 634-6570.

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ASK THE DOCTOR

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Q What information should the doctor give me about the medication?

A You must be told when the medication is expected to work. Some medications may work in 30 minutes. Others may take 8 weeks to be effective, and you should be aware of that expectation.

You must be told what side effects might be expected. Will the medication make your child sleepy or cause tics?

You should be told if the medication might interfere with any medication your child is taking or might take in the future.

Q How do I know if the medication is working?

A You should be told, in general, what to expect if the medication is helping. You may wish to ask your child's doctor specific questions, such as, "Will it be easier for Sally to concentrate at school, or be less emotional and angry at home?"

There might also be some measurable or objective way to assess the effectiveness of the medication for the problems being treated, even if it is just a behavioral questionnaire.

Q I have heard people say "Pills don't teach skills." Is medication really helpful to my child?

A There is often a misconception about the use of medication for behavior. The purpose is not necessarily to control the behavior outright, but rather to allow the individual to better control it him/herself, to give him/her more choices. "Pills don't teach skills" is still true today but medication may allow other interventions (whether they are educational or psychological) to be more effective. Medication should be viewed as just one part of an overall treatment plan, but it may be a very useful piece. Most important, do not be afraid to ask your child's doctor for more information. Your physician is there to help you and your child. **EP**

Daniel B. Kessler, MD, FAAP, is the Director of Developmental and Behavioral Pediatrics at the Children's Health Center of St. Joseph's Hospital and Medical Center in Phoenix, AZ. He is also a Clinical Associate Professor of Pediatrics at the University of Arizona College of Medicine.

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Circle #47

FAMILIAR FACES

Kayla Eleanor Taft, 9, loves ballet and has been taking lessons for five years. Kayla was born three months premature with cerebral palsy. She endured four leg surgeries, which enabled her to walk. Kayla attends the third grade at St. John the Baptist School. She swims at the local YMCA and has therapeutic horseback riding lessons, which she loves. Says her mom, Shirley, "I am very proud of her and wouldn't change her for anything." Kayla lives in Everson, PA, with her mom, her dad Frank, and two brothers, Jason, 13, and Travis, 5.

Darrien Patrick Fann, 5, enjoys playing with his two sisters, **Dawnn**, 2 (left), and **Dana**, 3 (right). Darrien has spastic quadriplegic cerebral palsy. He is a very bright and happy child, says his mom, Carla, and he attends pre-k in the local school district. Darrien enjoys singing, watching videos (Barney is a favorite), going to church, and playing hide-and-seek with his sisters. He lives in Shaker Heights, OH, with his mom, dad, Donald, sisters, and older brother, Charles, 17.

Teddy, 10 (left), and **Danny Bedrossian**, 9, are brothers and best friends! Teddy has translocation of chromosomes 10 and 12. He also has a seizure disorder and is nonverbal. According to his mom, Laura, however, Teddy has a great sense of humor! He attends Elwyn School in Media, PA. His favorite activity is playing with Danny. Danny makes up and performs plays, and provides endless entertainment for Teddy, his number one fan. He also takes Teddy for walks, and the two brothers enjoy watching TV. Teddy and Danny live with their mom and their dad, Ned, in Springfield, PA.

Would you like to share a favorite candid snapshot or slide of your child and/or family with other readers of *EXCEPTIONAL PARENT*? Send it to: Readers' Photos, *EXCEPTIONAL PARENT*, 555 Kinderkamack Road, Oradell, NJ 07649-1517. (Please do not send originals or "one-of-a-kinds" as we regret that photos cannot be returned.)

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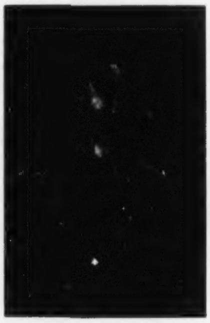
Caroline McCafferty Larson, 18, is a very talented painter! Caroline has WAGR syndrome (a rare genetic syndrome in which there is a predisposition to several conditions including certain malignancies, eye abnormalities, and/or mental retardation). In 1999, Caroline's art work won the Helen Keller National Art Show. Caroline is a residential student at the Tennessee School for the Blind. She loves music and movies and performing in school productions. She spends school holidays at home in Valdosta, GA, with her mom, Kelly, stepdad, Len, and little sister, Laura, 6.



According to his parents, Bob and Ann, **Benjamin Aaron Lucero**, 11, is loved by all who meet him. Ben has autism and enjoys attending J.W. Coon Elementary School. Some of his favorite activities are going swimming, playing outdoors with his golden retriever, Harold, and visiting his MeMa (grandmother). Ben lives in Fayetteville, NC, with his parents and brother Josh,

Will Wolfert, 7, practices his reading by studying the TV Guide! Will has cerebral palsy, uses a walker, has limited verbal skills, and is fed via g-tube because of swallowing difficulties. He loves watching TV, and his favorite shows are Thomas the Tank Engine, Barney, and Wheel of Fortune. Will is also a fan of roller coasters. According to his parents, Valinda and Steve, Will is fully included in first grade, and receives resource room assistance. Will and his family live in Dallas, TX.

Now on the Web! *We will now be including Familiar Faces and Children's Page on our Web site, www.eparent.com. Please send us your photographs with the understanding that doing so gives Exceptional Parent permission to put the photos on the Exceptional Parent Web site, exactly as they appear in the magazine and with the same text.*

On a separate sheet of paper, write your child's full name, age at the time the photo was taken, address and daytime phone number. Please identify everyone in the photo. If you like, you can also write a few sentences about your child. Then look for a familiar face in an upcoming issue!

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Special Education
Let us not turn back the clock

by Maxwell J. Schleifer, PhD

The Governor of Massachusetts is asking the state legislature to change the law governing special education so that the Commonwealth can save a great deal of money. He has told the legislature to have the courage to face parents who will make emotional appeals. His major concern is that 17 percent of all students are classified as having special needs, putting Massachusetts above the national average of 11 percent. He is also alarmed that 25 percent of the budget is used for students with special needs, and that state standard is the maximum possible opportunity rather than the Federal standard. Years ago, with bipartisan support, Massachusetts was at the forefront in legislation and support for youngsters with difficulties in learning. They used to pride themselves as being the model for innovative national legislation.

These new attitudes, however, are shaping similar efforts to cut services throughout the country. Let us look at the facts:

- In Massachusetts, students with disabilities are succeeding at a higher rate than other states—they have higher graduation rates, lower dropout rates, and higher rates of eventual inclusion in regular education. We should be concerned that special education statistics are not reflecting the true number of students with special needs in our state. We should wonder how many children are being penalized as a result of not being identified.
- By comparing the number of children with special needs to the money spent on them, they are implying that the costs of educating youngsters with special problems should not cost any more than regular education. This fosters comments by parents and teachers that children with special needs are getting an unfair share of the education budget.

There is a simple remedy. There is more tax money available at national and local levels than ever before. We should be providing all parents with the "maximum possible benefit" for all children instead of denying it to the most vulnerable group. We can afford to increase the overall budget rather than cutting a specific area. There is a sentiment not to add money without having accountability. This a reasonable request, and we should increase the budget for monitoring all programs and restore the serious budget cuts that have made evaluation so difficult.

Following is a statement issued by the Catholic Bishops of Massachusetts: Cardinal Bernard Law, archbishop of Boston; the Most Reverend Sean O'Malley, OFM Cap, bishop of Fall River; the Most Reverend Thomas Dupre, bishop of Springfield; and the Most Reverend Daniel Reilly, bishop of Worcester. The Bishops are the only group who have spoken in this debate about the importance of the dignity of each child and have best expressed a logical argument.

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STATEMENT ON SPECIAL EDUCATION

—As Bishops, each of us is pastor first. And, as pastors, perhaps among the most beautifully challenging task we have is the nurturance of those parents who are raising special needs children. Many of our children with severe disabilities are alive today as a result of modern medicine and their parents' love and prayers. They bring great joy and love to their families and remind us all of God's great love.

These young ones with obvious physical as well as those with hidden disabilities, students in both public and non-public schools, have as much claim on the concern of society and its policy-makers as their non-disabled peers do.

We are deeply troubled, therefore, by a public debate on special education that applies a simple cost benefit analysis to attempt to measure the value of these precious human lives. We are most concerned about the further marginalization of our disabled children in their own local communities—a marginalization resulting from their programming needs and the costs associated with them. No family should be made to feel guilt and shame over the educational needs of their children.

Therefore, we strongly urge the Governor and the members of the General Court to preserve Massachusetts' "Maximum Feasible Benefit" standard in special education as part of the Commonwealth's special education statute. Even with today's strong laws, too many parents constantly struggle to obtain the necessary services for their children. The "Maximum Feasible Benefit" standard is essential to overcoming the prejudicial views about the limited potential of disabled students and (to) freeing them to develop their God-given potential.

We pray for you, our public officials, as we pray for the parents of disabled children in our Commonwealth. Our hope and expectation is that you would be guided by what is best—and what is most just—for these very special children.

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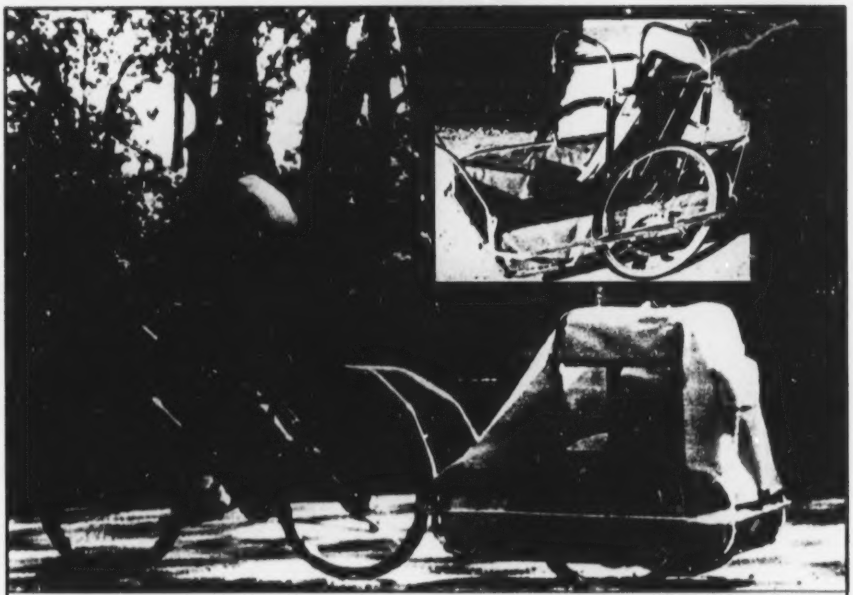

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MEDICAL RESEARCH UPDATE

Compiled by David Chamalian

HEARING IMPAIRMENTS: EARLY DETECTION SHOWN TO KEEP SIGN-LANGUAGE DEVELOPMENT STRONG

Dr. Christine Yoshinaga-Itano and her research team from the University of Colorado at Boulder report that children are not being screened early enough for possible hearing impairments. As a result, sign language development suffers. "Studies of more than 350 deaf and hard-of-hearing children show a very short critical period of normal language development in this population." According to the study, when screening of newborns was done—through state and federal grants—congenital hearing loss was identified at a median age of 2 months (the average age of hearing impairing identification is 2.5 years). 90 percent of the children identified as deaf by the age of 6 months achieved a vocabulary level in sign language that fell within the range of normal. Of the children diagnosed later in their lives, only the top 25 percent acquired a level of vocabulary comparable to that of the bottom 10 percent of children with normal language development. Research results were presented at a meeting of the American Association for the Advancement of Science in February 2000.

EXPERIMENTAL ASTHMA DRUG MAY ALLOW FOR SHARP REDUCTIONS IN USE OF STANDARD ASTHMA DRUGS

Taken by injection monthly, or in some cases, bi-monthly, the new drug, known as anti-IgE, is shown to be a new weapon in the battle against asthma. Researchers say that anti-IgE even stops asthma attacks before they occur, eliminating damage to the airways due to scarring. It has also been found to provide relief from allergies, including dust, mold, and pollens, and it carries no major side effects. Study researcher Henry Milgrom of the National Jewish Medical and Research Center claims, "We have a drug that's beneficial, safe, and may reduce the need for other medications." Anti-IgE still awaits FDA approval; however, clinical tests done on children and adults show that most people who took the drug regularly were able to eliminate other medications altogether or sharply reduce their use. Test results were released by the American Academy of Allergy Asthma and Immunology in San Diego, CA, and reported in the March 6, 2000 issue of *USA Today*.

BOYS WHO USE PREDNISONE TO TREAT CYSTIC FIBROSIS SHOW LONG-TERM GROWTH IMPAIRMENT, EVEN AFTER THE DRUG IS DISCONTINUED

A recently completed study of children, ages 6 to 14, receiving either prednisone to treat cystic fibrosis or a placebo found that boys using the prednisone showed a "significant" growth impairment compared to boys receiving the placebo, even after the drug treatment had been halted many years before. The research was done by Dr. Hui-Chuan Lai, from the University of Wisconsin School of Medicine. After tracking the children for 6 to 7 years after the last use of prednisone, Dr. Lai and her research team found that the average height among boys 18 years and older was 4 cm less in the drug group than it was in the placebo group. (Girls showed no signs of growth impairment.) "Physicians need to be aware," explained Dr. Lai, "of the side effects of steroid-based therapy. Many physicians have believed that the patients can catch up after the drug has been stopped. Therefore, they need to...aggressively monitor the patient's progress [and] use the minimum effective dose possible. The benefits of prednisone need to be weighed against the side effects...." The study can be found in the March 23rd issue of the New England Journal of Medicine and is accompanied by an editorial commentary on the research by Dr. Pamela Davis and Dr. Carolyn M. Kercsmar of Rainbow Babies and Children's Hospital in Cleveland, OH.

EFFECTIVE, NEW, ALUMINUM-FREE TREATMENT FOR INFANTS WITH GASTRO-ESOPHAGEAL REFLUX

The results of a study done in the UK by Dr. S. Miller indicate the effectiveness of an aluminum-free alginate preparation in treating infants with this gastro-esophageal reflux, which is characterized by persistent vomiting beginning soon after birth. (The vomiting associated with this disorder ocurrs when increased abdominal pressure forces gastric acid back up into the esophagus.) The infants, ranging in ages from 0 to 12 months, were given either the aluminum-free alginate or a placebo over a 14-day period. Infants receiving the alginate preparation showed a "statistically significantly lower" frequency of vomiting/regurgitation episodes than did the ones receiving the placebo. In addition, the severity of the vomiting episodes in the alginate group was less than in the placebo group. The percentage of symptom-free days in the former group was significantly lower as well. (Sixty percent of infants with this disorder recover completely—without treatment—after 18 months of age. Treatment, however, is necessary to prevent the onset of dehydration, loss of weight, and esophagitis, which can result from excessive vomiting, and to ease the anxiety and distress experienced by both the parents and child.) This study was published in Current Medical Research and Opinion, Volume 15, No. 3.

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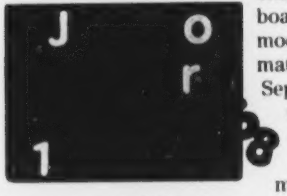

This language and math activity board is designed for children with low vision. The board is 16" x 12" and can accommodate four lines of writing or mathematical equations. Separate sets are available for upper case magnetic letters, lower case letters, and numbers/operations. This magnetic board is large enough for group or individual use.

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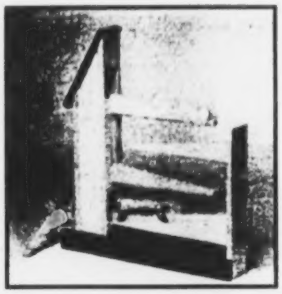

This wooden toy is designed for children with visual and cognitive disabilities. Using a hammer, the child strikes a lever and sends a wood roller up through a tube-like "house" and onto the top bar. The roller then rolls and drops in zigzag fashion through a series of bars and returns to its "launching" site. The child can watch the roller's journey back and forth from the top bar to the bottom bar, mimicking the eye tracking involved in reading tasks. The hammer striking action, reinforced by the satisfying "smack," also can aid in gross motor development.

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The ABLEDATA database of assistive technology and rehabilitation equipment contains information on more than 25,000 products for persons of all ages who have a physical, cognitive, or sensory disability. Products are chosen for this page by the ABLEDATA staff based on their specific applicability to or design for children who have disabilities. ABLEDATA, operated by Macro International Inc., is funded by the National Institute on Disability and Rehabilitation Research under contract number HN-96015001.

For more information on these and other assistive devices, or to submit product information for the database (and possible inclusion on this page), contact: **ABLEDATA, 8401 Colesville Rd., Ste. 200, Silver Spring, MD 20910; (800) 227-0216 or (301) 608-8998 (voice); (301) 608-8912 (TTY); (301) 608-8958 (fax); Web site: http://www.abledata.com.**

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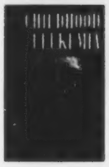

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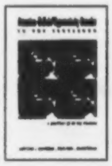

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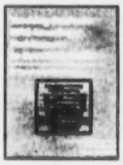

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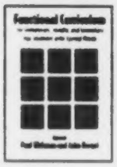

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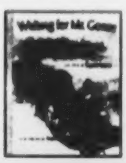

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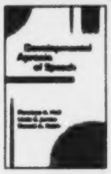

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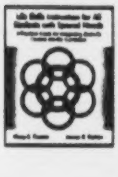

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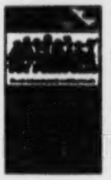

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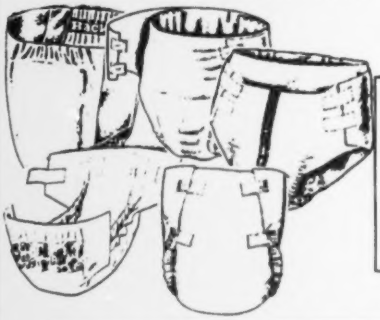

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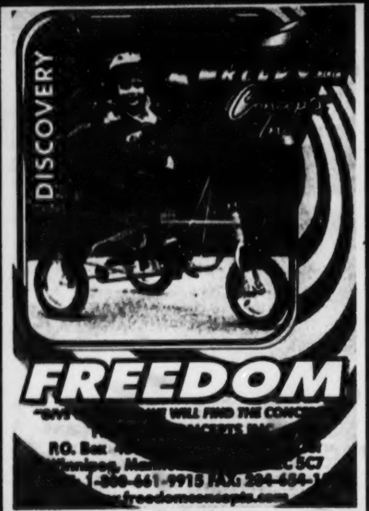
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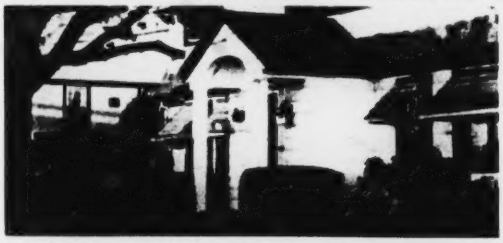

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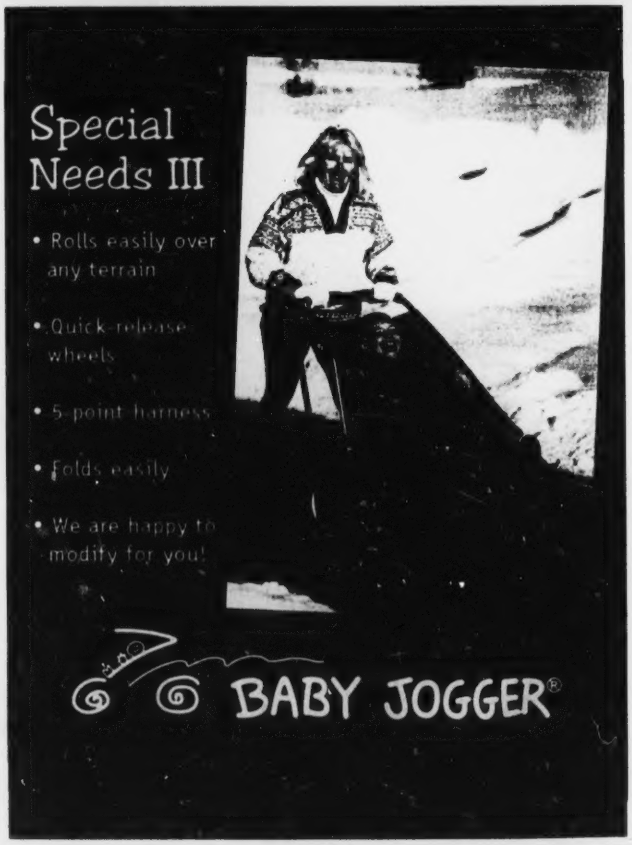
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And don't forget the pictures, pictures, pictures! There's always the chance that your photos will make a great shot for September's cover!

DEADLINE: JULY 1, 2000

Send nominations to: **Education Awards**

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"I Look Up to You, Jimmy"

by Suzy Bucher

Jimmy has always been a great brother to my sister Katie and me. He has also been a teacher to me, and he has taught me to accept other people no matter how different they may be. I am 12-years old, and I have looked up to Jimmy throughout my life.

Jimmy, 23, has autism, and cerebral palsy in his hands. Up until last year, he lived in our house. He now lives with two other young men in a group home in Ellicott City, MD. There he has a counselor to help him become more independent. He also spends his days working in the kitchen at Wendy's. There he has learned to become a better worker with the help of his job coach.

When I was little, people would ask me about my family and whether I had any brothers or sisters. I would answer, "I have a mommy, a daddy, a sister, and a Jimmy." I said this because he is not your everyday brother who picks on you and puts gum in your hair. He buys me presents and gives me hugs and kisses, and when I was little he sang to me. He is never mean to me.

Above: Jimmy Bucher and family (from l-r: Suzy, Jimmy's father Rich, Jimmy, Katie, and Jimmy's mother Pat) are all smiles as Jimmy took first place in the mile and long jump at Maryland State's Special Olympics. Below: Jimmy's dad and sisters cannot say enough about the joy Jimmy has brought to their lives.

Katie, my 20-year-old sister, and Jimmy and I love to spend time together. Sometimes we all go out to the movies, the mall, out to eat, or to amusement parks together. When Katie is not around, Jimmy and I either hang out or do sports. When I tell people my brother has a disability, sometimes they ask me what is wrong with him. When I hear this it hurts me even though they do not mean it. Nothing is *wrong* with Jimmy; it is what is *special* about him. It is also what he is *able* to do that others are not.

When I am with Jimmy in a public place, people look at him and treat us differently. A lot of times they go out of their way to act extra kind to him. But sometimes I think they would be more respectful if they did not treat him like a little boy, but be as kind to Jimmy as they would to any other person his age.

Jimmy does not judge people by the way they look. He sees the person's kindness as the biggest factor. He cannot tell another person's race, and I look up to him for this. I wish more people could be like Jimmy in that way.

Jimmy is always willing to help people. He does not complain when you ask him to do things for you, but he is actually happy to help out. I also look up to him as a teacher, a friend, and a brother. Many people act like they feel sorry for me when I tell them I have a brother with a disability. But I know that for me, having Jimmy as a brother is an advantage, a chance to learn something.

Sometimes I can tell that other people would like to "fix" Jimmy, but I love him just the way he is. **EP**

Mom's turn:

Jimmy has adored Suzy since the day I brought her home. Although Jimmy can seem detached, I loved to watch what she brought out in him. He never sang, ever, but he sang songs to her—songs I didn't even know he knew the words to. Now that they are older, he often expresses concern about her and loves when she comes to visit.

Dad's turn:

Largely because of Jimbo, I feel that I have two daughters who are two of the kindest people I know. I think my wife and I have grown closer because of Jimmy, and what he brings to our family. Even though both of us are teachers, he has been our teacher in many ways. I have learned so much and changed so much.

The Children's Page welcomes contributions from children who have disabilities, their siblings, and their friends. Be creative! Send your stories, photos and/or artwork to: **Children's Page,** *Exceptional Parent,* 555 Kinderkamack Road, Oradell, NJ 07649-1517. **Be sure to include your name, address, and day-time telephone number!** Now on the Web! We will now be including **Familiar Faces** and **Children's Page** on our Web site, www.eparent.com. Please send us your photographs with the understanding that doing so gives Exceptional Parent permission to put the photos on the Exceptional Parent Web site, exactly as they appear in the magazine and with the same text.

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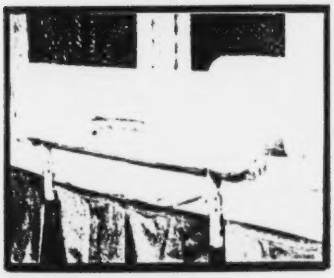

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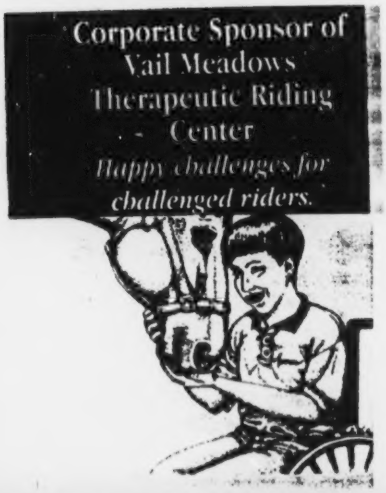

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The following is a brief summary. Please see package insert for full prescribing information.

CLINICAL PHARMACOLOGY

CARNITOR® (levocarnitine) is a naturally occurring substance required in mammalian energy metabolism. It has been shown to facilitate long-chain fatty acid entry into cellular mitochondria, therefore delivering substrate for oxidation and subsequent energy production. Fatty acids are utilized as an energy substrate in all tissues except the brain. In skeletal and cardiac muscle they serve as major fuel. Primary systemic carnitine deficiency is characterized by low plasma, RBC, and/or tissue levels. It has not been possible to determine which symptoms are due to carnitine deficiency and which are due to the underlying organic acidemia, as symptoms of both abnormalities may be expected to improve with carnitine. The literature reports that carnitine can promote the excretion of excess organic or fatty acids in patients with defects in fatty acid metabolism and/or specific organic acidopathies that bioaccumulate acyl CoA esters.

Secondary levocarnitine deficiency can be a consequence of inborn errors of metabolism. CARNITOR® may alleviate the metabolic abnormalities of patients with inborn errors that result in accumulation of toxic organic acids. Conditions for which this effect was demonstrated are: glutaric aciduria II, methyl malonic aciduria, propionic acidemia, and medium chain fatty acyl CoA dehydrogenase deficiency. Autointoxication occurs in these patients due to the accumulations of acyl CoA compounds that disrupt intermediary metabolism. The subsequent hydrolysis of the acyl CoA compound to its free acid results in acidosis that can be life threatening. Levocarnitine clears the acyl CoA compound by formation of acyl carnitine which is quickly excreted.

Levocarnitine deficiency is defined biochemically as abnormally low plasma levels of free carnitine, (less than 20 µmol/L at one week post term) and may be associated with low tissue and/or urine levels. Further, this condition may be associated with a ratio of plasma ester/free levocarnitine levels greater than 0.4 or abnormally elevated levels of esterified levocarnitine in the urine. In premature infants and newborns, secondary deficiency is defined as plasma free levocarnitine levels below age related normal levels.

BIOAVAILABILITY/PHARMACOKINETICS

In a relative bioavailability study in 15 healthy adult male volunteers CARNITOR® Tablets were found to be bio-equivalent to CARNITOR® Oral Solution. Following the administration of 1980 mg b.i.d., the maximum plasma concentration level (C_{max}) was 80 nmol/mL and the time to maximum concentration (T_{max}) occurred at 3.3 hours. There were no significant differences for AUC and urinary excretion observed between these two formulations.

In the same bioavailability study of 15 healthy adult males, CARNITOR® (levocarnitine) Injection administered as a slow 3 minute bolus intravenous injection at a dose of 20 mg/kg showed that free levocarnitine plasma profiles are best fit by a two compartment model. Approximately 76% of free levocarnitine is eliminated in the urine. Using plasma levels uncorrected for endogenous levocarnitine, the mean distribution half life was 0.585 hours and the mean apparent terminal elimination half life was 17.4 hours following a single intravenous dose.

The absolute bioavailability of L-carnitine from CARNITOR® Tablets and Oral Solution was determined compared to the bioavailability of L-carnitine from CARNITOR® Injection Intravenous in 15 healthy male volunteers. After correction for circulating endogenous levels of L-carnitine in the plasma, absolute bioavailability was 15.1% ± 5.3% for L-carnitine from CARNITOR® Tablets and 15.9% ± 4.9% from the Oral Solution.

Total body clearance of L-carnitine (Dose/AUC including endogenous baseline levels) was a mean of 4.00 L/hr. Endogenous baseline levels were not subtracted since total body clearance of L-carnitine does not distinguish between exogenous sources of L-carnitine and endogenously synthesized L-carnitine. Volume of distribution of the intravenously administered dose above baseline endogenous levels was calculated to be a mean of 29.0 L ± 7.1 L (approximately 0.39 L/kg) which is an underestimate of the true volume of distribution since plasma L-carnitine is known to equilibrate slowly with, for instance, muscle L-carnitine.

L-carnitine was not bound to plasma protein or albumin when tested at any concentration or with any species including the human.

INDICATIONS AND USAGE

CARNITOR® (levocarnitine) is indicated in the treatment of primary systemic carnitine deficiency. In the reported cases, the clinical presentation consisted of recurrent episodes of Reye-like encephalopathy, hypoketotic hypoglycemia, and/or cardiomyopathy. Associated symptoms included hypotonia, muscle weakness and failure to thrive. A diagnosis of primary carnitine deficiency requires that serum, red cell and/or tissue carnitine levels be low and that the patient does not have a primary defect in fatty acid or organic acid oxidation (see Clinical Pharmacology). In some patients, particularly those presenting with cardiomyopathy, carnitine supplementation rapidly alleviated signs and symptoms. Treatment should include, in addition to carnitine, supportive and other therapy as indicated by the condition of the patient.

CARNITOR® (levocarnitine) is also indicated for acute and chronic treatment of patients with an inborn error of metabolism that results in a secondary carnitine deficiency.

CONTRAINDICATIONS

None known.

WARNINGS

None.

PRECAUTIONS

General

CARNITOR® (levocarnitine) Oral Solution is for oral/internal use only.

Not for parenteral use.

Gastrointestinal reactions may result from too rapid consumption of carnitine. CARNITOR® (levocarnitine) Oral Solution may be consumed alone, or dissolved in drinks or other liquid foods to reduce taste fatigue. It should be consumed slowly and doses should be spaced evenly throughout the day to maximize tolerance.

Carcinogenesis, mutagenesis, impairment of fertility

Mutagenicity tests performed in *Salmonella typhimurium*, *Saccharomyces cerevisiae*, and *Schizosaccharomyces pombe* indicate that CARNITOR® (levocarnitine) is not mutagenic. Long-term animal studies have not been conducted to evaluate the carcinogenicity of the compound.

PREGNANCY

Pregnancy Category B.

Reproductive studies have been performed in rats and rabbits at doses up to 3.8 times the human dose on the basis of surface area and have revealed no evidence of impaired fertility or harm to the fetus due to CARNITOR®. There are, however, no adequate and well controlled studies in pregnant women. Because animal reproduction studies are not always predictive of human response, this drug should be used during pregnancy only if clearly needed.

NURSING MOTHERS

It is not known whether this drug is excreted in human milk. Because many drugs are excreted in human milk, a decision should be made whether to discontinue nursing or to discontinue the drug, taking into account the importance of the drug to the mother.

PEDIATRIC USE

See Dosage and Administration.

ADVERSE REACTIONS

Various mild gastrointestinal complaints have been reported during the long-term administration of oral L- or D,L-carnitine; these include transient nausea and vomiting, abdominal cramps, and diarrhea. Mild myasthenia has been described only in uremic patients receiving D,L-carnitine. Gastrointestinal adverse reactions with CARNITOR® (levocarnitine) Oral Solution dissolved in liquids might be avoided by a slow consumption of the solution or by a greater dilution. Decreasing the dosage often diminishes or eliminates drug-related patient body odor or gastrointestinal symptoms when present. Tolerance should be monitored very closely during the first week of administration, and after any dosage increases.

Seizures have been reported to occur in patients with or without pre-existing seizure activity receiving either oral or intravenous levocarnitine. In patients with pre-existing seizure activity, an increase in seizure frequency and/or severity has been reported.

OVERDOSAGE

There have been no reports of toxicity from carnitine overdosage. The oral LD_{50} of levocarnitine in mice is 19.2 g/kg. Carnitine may cause diarrhea. Overdosage should be treated with supportive care.

DOSAGE AND ADMINISTRATION

CARNITOR® (levocarnitine) Tablets

Adults: The recommended oral dosage for adults is 990 mg two or three times a day using the 330 mg tablets, depending on clinical response.

Infants and children: The recommended oral dosage for infants and children is between 50 and 100 mg/kg/day in divided doses, with a maximum of 3 g/day. Dosage should begin at 50 mg/kg/day. The exact dosage will depend on clinical response.

Monitoring should include periodic blood chemistries, vital signs, plasma carnitine concentrations and overall clinical condition.

CARNITOR® (levocarnitine) Oral Solution
For oral use only. **Not for parenteral use.**

Adults: The recommended dosage of levocarnitine is 1 to 3 g/day for a 50 kg subject, which is equivalent to 10 to 30 mL/day of CARNITOR® (levocarnitine) Oral Solution. Higher doses should be administered only with caution and only where clinical and biochemical considerations make it seem likely that higher doses will be of benefit. Dosage should start at 1 g/day, (10 mL/day), and be increased slowly while assessing tolerance and therapeutic response. Monitoring should include periodic blood chemistries, vital signs, plasma carnitine concentrations, and overall clinical condition.

Infants and children: The recommended dosage of levocarnitine is 50 to 100 mg/kg/day which is equivalent to 0.5 mL/kg/day CARNITOR® (levocarnitine) Oral Solution. Higher doses should be administered only with caution and only where clinical and biochemical considerations make it seem likely that higher doses will be of benefit. Dosage should start at 50 mg/kg/day, and be increased slowly to a maximum of 3 g/day (30 mL/day) while assessing tolerance and therapeutic response. Monitoring should include periodic blood chemistries, vital signs, plasma carnitine concentrations, and overall clinical condition.

CARNITOR® (levocarnitine) Oral Solution may be consumed alone or dissolved in drink or other liquid food. Doses should be spaced evenly throughout the day (every three or four hours) preferably during or following meals and should be consumed slowly in order to maximize tolerance.

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Come Together

A mother's love, a daughter's triumph

Heidi Van Arnem was a typical 16-year-old who loved to swim, ski, sail and hang out with her friends. That all changed on March 24, 1983, when a gunshot wound to her neck severed Heidi's spinal cord and left her a quadriplegic.

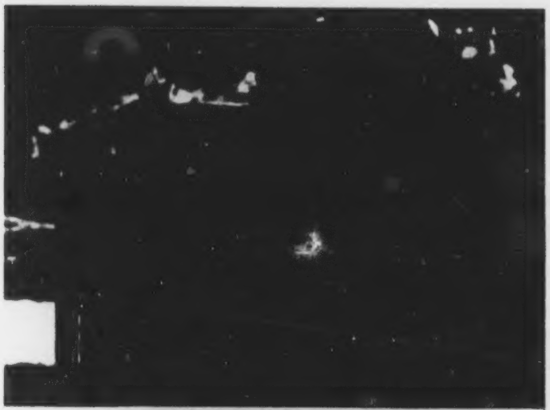
"For 36 hours in the intensive care unit, I laid upside down with four straps across my body to keep me from moving," Heidi recalls. "My body continuously convulsed and tears formed a puddle on the floor below me. Every sound caused tremendous pain. I was informed at this time that I was paralyzed from the neck down. It was the first moment of realization of my life to come."

Love and support from family -- led by the steely determination of her mom, Karen – transformed Heidi's tragedy into a life of hope and promise. "She was there for me, right from the beginning," says Heidi. Karen accompanied her daughter to Colorado for five months of rehabilitation after remarrying only one month before. Meanwhile, new stepdad Paul Zosel took on the responsibility of caring for the other four children. Once Heidi returned home, her siblings made sure that she got out and was not limited by barriers. "We refused for Heidi to miss out on things," says youngest sister Heather. "If there were 10 flights of stairs and no other way up, we carried her up 10 flights of stairs."

But it was her mom who had the biggest impact on Heidi. "The obstacles Heidi faced at the time were tremendous, but I never said, 'Let's wait for Heidi to feel better,' or 'Let's wait a year for her to go back to school.'" Karen says, "She was going to finish school. She was going to college. We never allowed an option not to go," says Karen. Even as she dealt with her own grief after Heidi's accident, Karen stayed strong for her daughter. She let Heidi cry and get angry, then she took charge of toughening her up.

A mother's tough love paid off. Seventeen years later, Heidi is the owner of iCan, Inc., a comprehensive Web site for the disability community. The goal of iCan is to open the door of opportunity for the millions of people with disabilities worldwide and their families, and improve their quality of life.

Heidi says in recognition of her mother's efforts: "As a parent, what you do, what you say and how you say it makes a difference in your child's life. One person's love and support can be the initial push that separates those that overcome and achieve by doing from those that wait a lifetime for things to get better."



Photos from top: Heidi at age four; Heidi and Karen at Karen's wedding; The Van Arnem/Zosel family; Heidi today - strong, confident and ready to make a difference.

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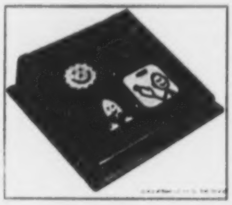

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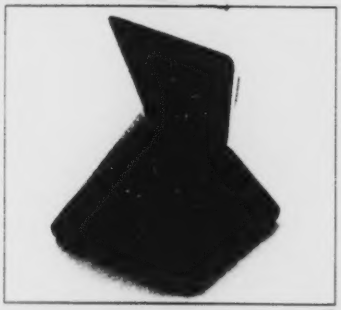

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Sensory Adventure Camp is a fun and innovative motor and sensory experience for children with developmental delays.

Cover: Gold on the green! Two members of the Special Olympics New Jersey golf team, Robert Elfreth (front) of Haddon Heights, NJ, and Denis G.T. Hagios of Flemington, NJ, who both brought home the gold at the World Games, read the green for a clean shot. For more information on adaptive golf, see "Tee Time for Everyone" on page 74.

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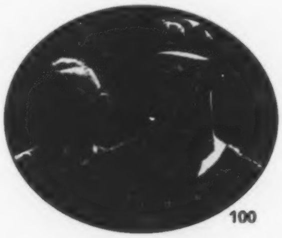

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- *To reach out to mothers and fathers of children and young adults who have disabilities and special healthcare needs.*
- *To empower parents and professionals by providing practical information and emotional support.*
- *To appreciate that parents are the most important experts in the lives of their children.*
- *To energize parents and professionals.*
- *To share ideas and experiences so parents, professionals, people who have disabilities, and other advocates can learn from one another and better collaborate to serve all children and families.*

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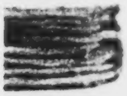

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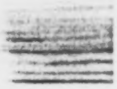

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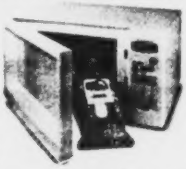

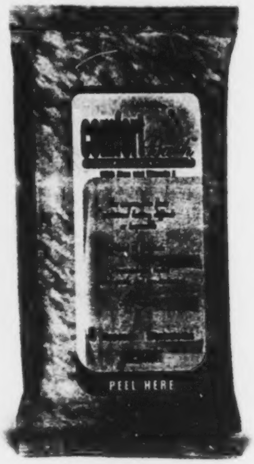

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editor's desk

Planning Each Year, Living Each Day, Three Decades Go By

June is the end of the school year for most elementary and secondary school students. For students with special needs, it is time for Individualized Education Planning (IEP). Plans are evaluated as to how well they have succeeded and been laid out to determine the best course of action for the following school year. Parents, and even professionals, can find the process of developing an IEP with the school personnel difficult. Even though everyone has the best interests of the child in mind, views of what this means can be quite divergent.

Maxwell J. Schleifer, PhD
Editor-in-Chief

Kathleen McCoy, PhD, in "A Proactive Role for Parents in IEPs," discusses the problems she encountered when her daughter, who has a mild learning disability, was making the transition from a middle school to high school. Dr. McCoy discovered the different organizational styles of the two schools, and the nature of the high school meant that she had to be more active if her daughter was to get the best attention. She developed a "communication system" that could be useful not only for high school students, but any time the youngster was making a transition from one school to another, whether because of changing grades or moving to a new community.

Our role model for this month, whom we also welcome into the Exceptional Parent Hall of Fame, is Martha Ziegler, founder and former executive director of The Federation of Special Needs Children in Boston, Massachusetts. She was one of the parents who not only advocated for her own child thirty years ago, when there were few, if any, programs, but helped create the systems and laws that serve all children with disabilities. She helped initiate a state law that was the model for the federal law, the Individuals with Disabilities Education Act. In the July issue, we will share the wisdom she has gained from forty years of raising and supporting the independence of a daughter with autism.

Technology

Technology has made an enormous difference in the lives of children with special needs and their families. The activities of daily living and learning can be enhanced with the help of technology, both high tech and low tech. Marilyn Hammond, PhD, describes in "Tech Around the House" some common devices like adjustable spoons and extended-reach combs that can give a child with a disability more independence. The Alliance for Technology Access is our Organizational Spotlight. Over twenty years ago, Jackie Brand organized this parent-led technology center for children. That one center has bloomed into a nationwide organization. They continue to be at the forefront of developing and advocating for the rights of children with disabilities to have access to appropriate technology resources in the classroom. They have just published the third edition of their book, "Computer and Web Resources for People with Disabilities." This book is completely revised and is a valuable resource. We have excerpted the section that describes the inclusion of technology in the IEP.

Thirty Years: Let the Celebrations Begin!

As we enter our thirtieth year of publication, we are sporting a new design on our cover and on the pages within the magazine. We hope you like our changes, and we invite you to send your feedback and suggestions. In addition to our new look, we will be celebrating our third decade throughout the year in various other ways. We would like to start by answering the question "Where are they now?" about people who have appeared in EP over our thirty-year history. We invite everyone to tell us what they are doing (and have been doing) since we last heard from them. All readers are invited to let us know what changes—whether in medical science, legislation, technology, advocacy, and methods in education—over the past years have affected them, whether for the better or for the worse. Send all comments on any subject to us at: Exceptional Parent Magazine, 555 Kinderkamack Rd., Oradell, NJ 07649-1517; Fax: (201) 634-6570; E-mail: epedit@aol.com. ■

Maxwell J Schleifer

special publisher's letter

A NEW LOOK
FOR THE NEW CENTURY

Joseph M. Valenzano, Jr.
President, CEO & Publisher

Dear Readers:

June 2000 marks the beginning of Exceptional Parent's thirtieth consecutive year of publishing. To celebrate this milestone we decided we would refresh our appearance and especially our cover design, which now incorporates EP as our new logo. This decision was not made lightly, and as with anything new, there is always opportunity for "fine tuning." We ask that you take a close look at what we have done—and let us know what you think. Since Exceptional Parent is and always will be for you, we want to make sure you understand why we did what we did and assure you that, if need be, we will change again until we get it right…for you.

Let me take a moment to explain the underlying rationale behind our new look. I have had the privilege of meeting so many dedicated, passionate, and committed people who represent the core of what Exceptional Parent is all about and what its mission has been and will continue to be: to provide a forum for sharing ideas and experiences, and to provide practical advice and support for families and professionals involved in the care and development of those with disabilities and special healthcare needs. One truly remarkable parent of two children with disabilities who recently lost one child to a long and difficult battle with a rare disorder, reminded me of what so many of us who are parents intuitively know but sometimes do not express. How was she able to do all she did and how could she still go on? She observed simply, "Once a parent, always a parent." It is very true. As I reflected on what parents have accomplished over the last thirty years, it seemed to me that it was both necessary and appropriate that we do something that gives testimony to the Parent Movement…the *EP* Movement, if you will. EP will always be about parenting, but it occurred to me that EP is about people…exceptional and extraordinary people. EP is more than an acronym; it stands for achievements—in caring, persistence, patience, professionalism, and by people who have disabilities.

Because of their great advocacy and determination on behalf of their children, the people we call exceptional parents have moved mountains. They have fashioned a position of respect for themselves and those they care for that is both enviable and enduring. On the sheer strength of their efforts, parents have pulled professionals into their fold. They have made believers out of physicians, therapists, teachers, and legislators. Parents no longer stand alone, they now stand side by side with professionals. The "P" in EP signifies that parents have become more professional, and professionals have become more parental and considerate of the needs and desires of parents. Are there exceptions to this? You bet there are. But, parents have made great strides, and our world and the world of children and adults with disabilities and special needs is far better today than it was thirty years ago. And it will be better still tomorrow, because of what you—parents, advocates, caregivers, direct support professionals, and all who read EP—have done.

Just as you have become far more than parents, EP has become far more than a magazine. Through our Web site, http://www.eparent.com, we now provide information at the touch of a button; the EP Library offers the largest single source of books and videos for people with disabilities and caregivers; and in November 2000, EP will bring together parents, families, professionals, and disability organizations from around the world for the first ever World Congress & Exposition on Disabilities.

EP is intended to represent all of you...the young children who have now grown into adults and who paved the way for those who are just embracing their challenges; parents and extended families who have, through steadfast love and caring and compassion, reinforced in us the basic premise of putting the person first, the disability second, because when you do this, anything is possible; the dedicated professionals who steadfastly adhere to the belief that all of us—those who are able bodied and those who have disabilities—deserve a chance to be the very best we can be and to make our own contribution to society.

We promise to never forget who we are or where we came from because we know that "once a parent, always a parent." Please share your comments or suggestions with us. We would like very much to hear from you.

Joseph M Valenzano Jr

Send all correspondence to:
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Search & Respond

About Search & Respond

Search and Respond is an opportunity for our readers to exchange information about their practical experiences in meeting the everyday challenges of life with a child or adolescent who has a disability. In this column, "S" represents Search letters and "R" represents Respond letters received to a previously printed Search. "Instant S&R" is a new feature which represents e-correspondence we have downloaded from our Web site. All Responds are forwarded to the writers of the original Searches; some are published. Published letters may be edited for purposes of space and clarity. We also expect parents to consult appropriate professionals.

When sending correspondence, please indicate whether it is a Search or a Respond. For Responds, be sure to note in which issue the original Search letter appeared. Please remember to include a phone number on all correspondence, in the event that more information is required. Write to: Exceptional Parent, Attn: Search/Respond, 555 Kinderkamack Rd., Oradell, NJ 07649-1517; Fax to: (201) 634-6570; E-mail to epedit@aol.com; or visit Search and Respond on our Web Site: http://www.eparent.com.

For information about specific disabilities, contact: the National Organization for Rare Disorders (NORD), 100 Rt. 37, PO Box 8923, New Fairfield, CT 06812; (800) 999-6673; (203) 746-6518; Web site: http://www.rarediseases.org. Also, see the "National Resources for Specific Disabilities" directory in Exceptional Parent's 2000 Resource Guide (January 2000, starting on page 30).

Each month, Chris Feudtner, MD, PhD, reviews Search & Respond for accuracy and completeness. Dr. Feudtner is a pediatrician at the Pediatric Care Center of the University of Washington in Seattle, and is currently a Robert Wood Johnson Clinical Scholar. Look for Dr. Feudtner's comments on certain Search & Respond letters.

S

Summer caregiver

Our daughter has partial trisomy 13 (a disorder involving an extra chromosome 13, resulting in abnormal brain development) and has speech and motor delays and some developmental delay. My husband and I work full-time. Our daughter has spent her summers in a neighborhood daycare center since kindergarten. This August she will turn 13, which is outside of the age group accepted by the center. I am thinking of putting an advertisement in the nearby university newspaper for a companion, maybe a student of special education, who would stay with her on weekdays in the summer and on school holidays. I would be interested in hearing what other parents in our situation have done or are doing for their adolescents with special needs.

J.T.
via the EP Web site

S

Genetics question

My 3-year-old daughter was born with the cloverleaf skull deformity (also known as Kleeblattschadel), which is a severe form of craniosynostosis characterized by premature fusion of the bones of the skull. She has had many surgeries and will require more. She also has a tracheostomy tube for breathing because her mid-face is compacted. She has had genetic testing, but it has not yielded answers into why she has this syndrome. I was wondering if anyone has been through this. I also wonder if they have any other children who were born without disabilities.

A.O.
Johnsonburg, Pennsylvania

S

Lip biting

I have a 12-year-old daughter who has cerebral palsy and a seizure disorder. She is fed and given her medication via g-tube. She takes medication to control seizures and to help with her high muscle tone and spasms.

For years, she has been biting her upper and lower lips. She bites her lips at all times of the day and night, with no pattern to it. It is very frustrating. She does not release the bite until she ends up with cut, bleeding, and swollen lips. No one, including her neurologist, pediatrician, or dentist, knows why she bites her lips or how to stop the behavior.

Additionally, my daughter does not sleep through the night. She will fall asleep at about 8:00 PM, wake up at about 1:00 AM, and not go back to sleep.

I hope someone can give me help with these issues.

P.M.
Ashland, Pennsylvania

S

Need a smaller pump

I have a 2-year-old daughter with cerebral palsy. She is currently tube-fed exclusively. We have a feeding pump that is becoming very cumbersome. We are in the process of getting a special wheelchair, but for now, she has to be carried because she starts screaming if she is put in a stroller. She only weighs 17 pounds, but after holding or carrying her most of the day, along with a large bag with the pump, my back is suffering. Medicaid is refusing to purchase a smaller pump. Does anyone have any suggestions on what we can do to get a smaller pump? I am a single mother on public assistance, and cannot work because I have to take care of my child.

L.R.
Bastrop, Texas

S

Adult children

My 21-year-old brother has Down syndrome and is currently attending occupational therapy classes. My parents and I are looking for a non-profit agency to help us find some type of work in a highly supervised environment so that when school is over, he has something to keep him occupied. We live in Queens, NY.

S.R.
via the EP Web site

My son is medically fragile. He has Leigh disease (a mitochondrial metabolic disorder that causes lesions of the brain, spinal cord, and optic nerve) along with other medical conditions. He has qualified for home nursing care for six years. He will soon be 21 and will no longer receive care under the Title 19 entitlement, which is his present source of funding (Title 19 is a federally supervised, state-administered medical assistance program). This will put him at great risk. He has LPN or RN care when we are

continued on page 20

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& Her Son Nicholas

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is the magazine for parents and professionals involved in the care and development of children and young adults with special needs, including Physical Disabilities, Developmental Disabilities, Mental Retardation, Autism, Epilepsy, Learning Disabilities, Perceptual Disabilities, Hearing Impairments, Vision Impairments, Emotional Problems, Chronic Illness.

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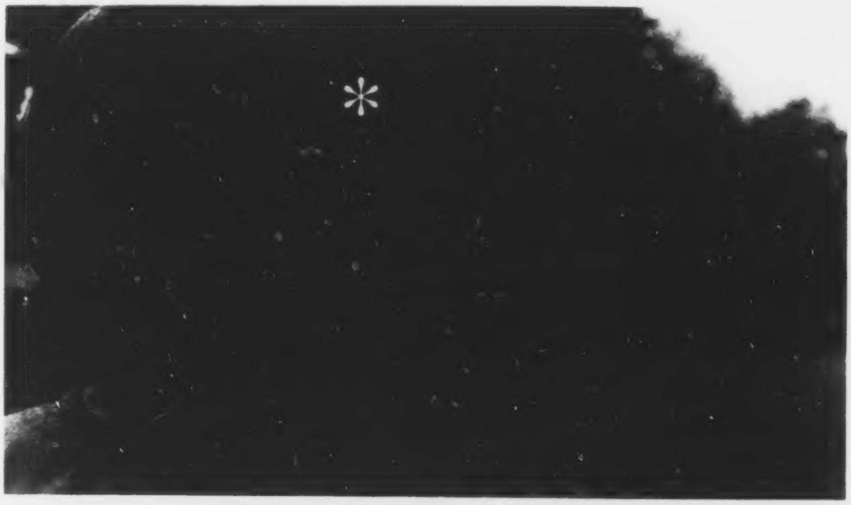

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Circle #25

continued from page 14

at work or sleeping. The agency would not send out anyone with less training because his case is too involved. Now, the government claims that a personal assistant can take care of him; or, if I use fewer hours, quit my job, lose my insurance, and stay home to take care of him full-time, I can hire a nurse for a few hours a week. My husband and I now care for our son weekdays from 5:00 PM until 11:00 PM, and on weekends. We love him and feel the best and safest place for him is at home, with a day program to attend when school ends. He wants to have somewhere to go and people to see. Because of his medical needs, most day programs will not accept him. We are looking for alternative funding sources as well as a day program capable of meeting our son's needs. We live in Lake County, Illinois.

S. and P.H.
via the EP Web site

R Wet clothes because of vesicostomy

C.S. (March 2000) has a 5-year-old daughter with spina bifida who has had a vesicostomy (a surgically created opening below the navel) so that her urine currently drains into her diaper and a surgical pad. When she moves around, her diaper pulls down and her pants and shirt get wet.

My 5-year-old daughter also has spina bifida. A vesicostomy was performed at birth. We used a booster pad (latex-free), which we ordered through a diaper company. We placed the lower half of the pad over the vesicostomy area and the other half down in the diaper. This allowed the urine to drain downwards and away from her clothes. Recently, our daughter underwent a bladder augmentation. This involves closing the vesicostomy and creating a stoma (artificial opening) through the navel. We are happy to say that she is completely dry and can catheterize herself.

R.B.
Frederick, Maryland

I have a 3-year-old daughter with spina bifida who had a vesicostomy when she was 26 months old. We had the same problem. Finally, we used adult bladder pads, placed lengthwise and high up past the waist line so that most of the sticky part of the pad is above the diaper and we stick the pad to her undershirt.

E.O.
Berkeley, California

Correction

In April's Search & Respond column, the phone number for Chromosome Deletion Outreach, Inc., was incorrect. The correct phone number is (561) 391-5098. They also have a toll-free number: (800) 236-6880. We regret this error.

Instant S&R

S Shaken baby syndrome

I am a single parent of a child who has traumatic brain injury. This was the result of being shaken by a daycare provider six years ago when he was 18 months old. I have exhausted local resources and now must look nationally for the best federal/state programs available for my situation. I have not been able to find much at all regarding assistance for the parent of a child with this type of disability.

H.T.
via the EP Web site

R I have a 3-year-old child with shaken baby syndrome. The Shaken Baby Alliance is a wonderful nonprofit organization, and a great place to find people and information. They have an E-mail list as well.

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EDITOR'S NOTE:

Please check out the Brain Injury Association Web site: http://www.biausa.org. They have many resources and much information available. Your local Parent to Parent group is also a great resource. For the group nearest you, call the Beach Center on Families and Disability at the University of Kansas. Their phone number is (785) 864-7600.

There are also groups called Parent Training and Information Centers. For one in your state, contact the Alliance Coordinating Office at the PACER Center. Their phone number is (888) 248-0822. You should also be aware of your state's Early Intervention Program. Each state has a central directory for parents seeking information about early intervention and other public and private resources for young children. For the number in your state, contact the National Early Childhood Technical Assistance Center (NECTAS) at the Frank Porter Graham Child Development Center at (919) 962-2001, or check out their Web site at http://www.nectas.unc.edu. One more resource is your local Arc. For the chapter nearest you, contact the national office at (800) 433-5255 or check out their Web site: http://www.TheArc.org.

S

Sports equipment for children with disabilities

My son is 8 years old and has spastic cerebral palsy, but is able to walk unaided and enjoys participating in as many sports as possible. However, he is almost always competing with non-disabled children. One of the sports he particularly enjoys is bowling. I have read about adaptive handles or holders for bowlers. I would like to find out more about this, but do not even know where to start.

K.F.
via the EP Web site

EDITOR'S NOTE:
Before we went to press, we heard from K.F., who contacted us to say she found adaptive bowling equipment from the Abilitations catalog. The phone number for catalog orders is (800) 850-8602. The company's Web address is http://www.abilitations.com. The American Wheelchair Bowling Association, Inc., has identified two companies that sell adapted bowling equipment. They are Flaghouse (800) 793-7900 and Maddak (800) 443-4926. Also, see New Products in this issue.

S

Drooling

I am the mother of 9-year-old girl with cerebral palsy. She is bright and beautiful, but we are in a constant battle against drooling. We have only tried one thing: a patch behind her ear, which caused her to develop a rash. Are there any treatments out there that were used by others to control drooling? I know about surgery, but we have undergone so many that I really would like to avoid it except as a last resort.

N.H.
via the EP Web site

R

My 8-year-old daughter used to have a drooling problem to the point where she went through about 12 bibs a day just to keep her clothes dry. We tried everything we could think of, from limiting her dairy and chocolate, constant wiping, and praise. Finally we consulted an ear, nose, and throat doctor who recommended surgery. That was two years ago. I have never been happier to put her through surgery (and we have had many). Now, the only time she drools is if she is sick or if she has had too much ice cream with chocolate sauce!

C.C.
via the EP Web site

DR. FEUDTNER:
The scopolamine patch, which is usually placed behind the ear, can also be placed elsewhere on the skin if putting the patch repeatedly in the same place causes irritation. Talk to your doctor first before trying it. Another medication for drooling, this one taken by mouth, is glycopyrolate.

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Circle #51

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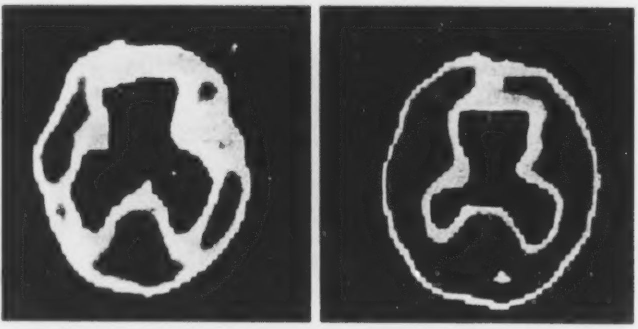

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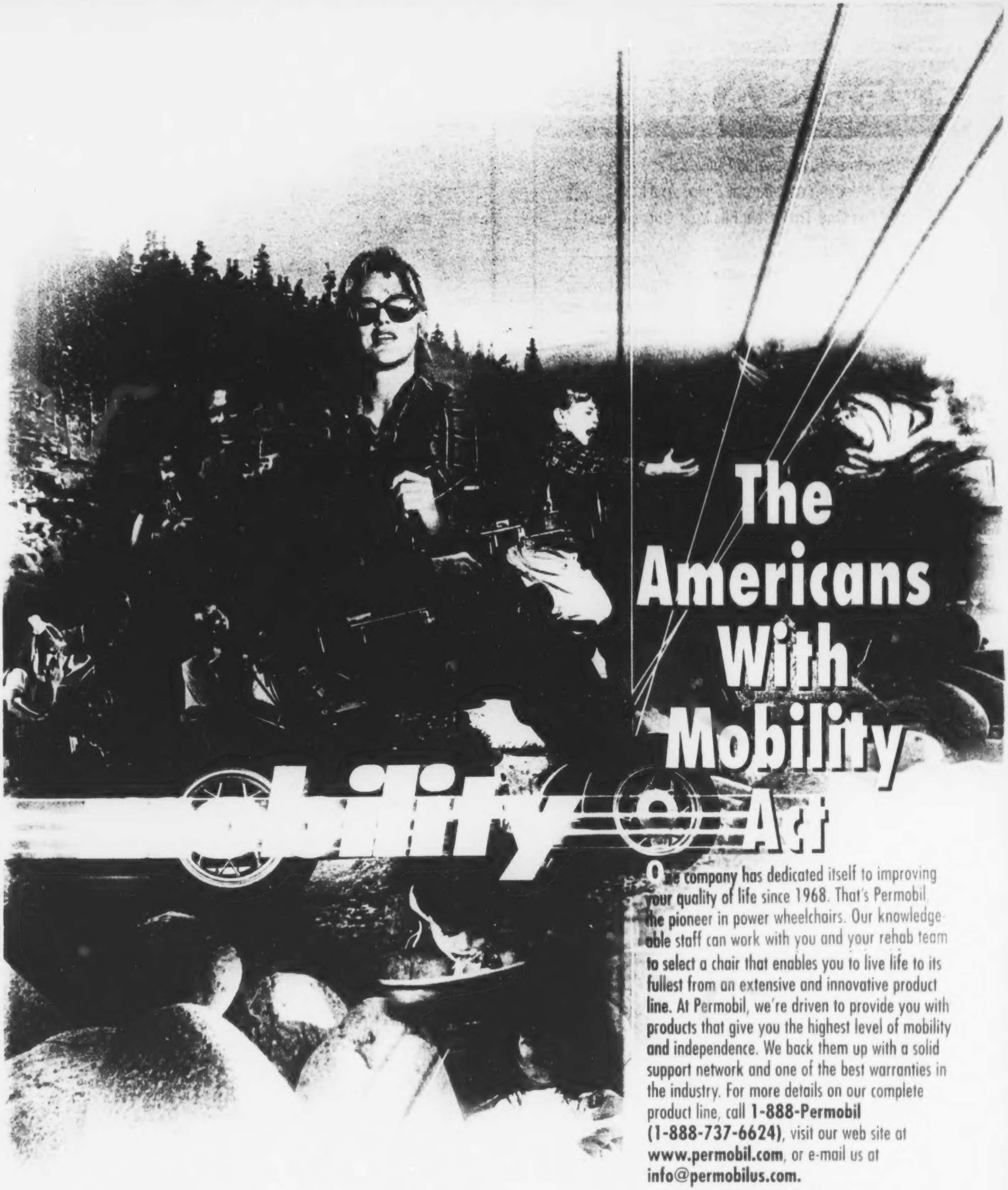

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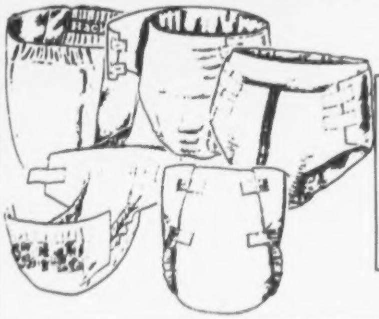

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Circle #29

Cast Your Vote!

This September, EXCEPTIONAL PARENT'S 28th Annual Education Issue Will Recognize:

MODELS OF EXCELLENCE IN EDUCATION

Awards for both Inclusive Education AND Specialized Programs

ALL GRADES: Pre-School THROUGH High School

Send us 600 words or less about specific educational programs that you think make school "cool" for children with disabilities and special needs.

Here are some areas where exceptional programs stand out:

- Inclusion.
- Parents' active involvement.
- Bringing the community into the classroom and the classroom into the community.
- How the school has put its philosophy into action.
- Ease of duplication of program(s).

And don't forget the pictures, pictures, pictures! There's always the chance that your photos will make a great shot for September's cover!

DEADLINE: JULY 1, 2000
Send nominations to: **Education Awards**
Exceptional Parent Magazine, 555 Kinderkamack Rd., Oradell, NJ 07649-1517

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Dear Parents:

When my son was born with cerebral palsy, my family and I had no idea how our lives would be affected. We did not see how vulnerable our child was and how he would need our care and protection for the rest of his life. We did not understand that we would become his life-line in so many ways, and he in turn would consume our lives.

As an attorney, I have become deeply involved in brain injury and other birth injury cases throughout the country.

We would be interested in looking into your child's birth if you had complications either during pregnancy, during delivery, or after delivery.

Our medical staff includes a board certified obstetrician and a registered obstetrical nurse.

Please call 1-800-888-LAWS and speak with either an attorney or a registered nurse.

Remember, there are time restrictions.

Sincerely,

Sheldon O Zisook

Sheldon O. Zisook
President

Lawyers Incorporated, P.C. is an Illinois licensed corporation with affiliated law firms throughout the United States.

July 26, 2000, is the tenth anniversary of the passage of the **Americans with Disabilities Act (ADA)**. The Act's passage helped to bring people with disabilities into the mainstream of American life. This victory celebration is for all Americans, including people with disabilities from diverse ethnic, racial, and cultural groups.

There will be many events scheduled to celebrate this occasion. The Spirit of ADA Relay will be held June 11-August 7 in major cities across the country. For information on the Relay and other local events celebrating the anniversary of ADA, log onto http://www.spiritofada.org. Click on the National Events Calendar for locations and information on specific events.

To learn about the American with Disabilities Act and your rights, contact the National Council on Disability, 1331 F Street NW, Ste. 1050, Washington, D.C. 20004 or visit NCD's award-winning Web site: (http://www.ncd.gov).

Children's Pen Pal Program

Children's Hopes & Dreams Wish Fulfillment Foundation's Pen Pal Program is now in its sixth year of matching children with chronic illness or disabilities from around the world to become pen pals. This free program, now in 53 countries, recently enrolled its 10,000th pen pal. Children in this program are matched by age (5-17), sex, and illness category. Enrollment cards are available by calling (973) 361-7366, or by writing to: Children's Hopes & Dreams Wish Fulfillment Foundation, 280 Rte. 46, Dover, NJ 07801.

Correction for April 2000, pg. 42

The NJ Back in Action Program is not under the auspices of RESNA or the Technical Assistance Project. It is under the auspices of the New Jersey Technology Assistive Resource Program (TARP), one of 56 projects funded by the U.S. Department of Education, National Institute on Disability and Rehabilitation Research. RESNA provides technical assistance to these projects. Their correct telephone number is (703) 524-6686.

JULY EVENTS CALENDAR

7/7-9 Amputee Coalition of America (ACA)

"BRIDGES TO THE FUTURE" 10TH ANNUAL MEETING AND EXPOSITION

ORLANDO, FL

Topics will include information on insurance, choosing a prosthesis, everyday living, as well as individual sessions on cancer, diabetes, and vascular disease.

For more information contact the Amputee Coalition of America, 900 E. Hill Ave., Ste. 285, Knoxville, TN 37915-2568; Phone: (888) 267-5669 or (865) 524-8772; Fax: (865) 525-7917; Web site: http://www.amputee-coalition.org.

7/19-23 The Seventh International Fragile X Conference

THE SHERATON UNIVERSAL HOTEL, LOS ANGELES, CA

Topics will include genetic counseling issues, X-linked mental retardation, educational intervention, and screening studies.

For more information contact the National Fragile X Foundation, PO Box 190488, San Francisco, CA 94119-0488; Phone: (800) 688-8765; Fax: (510) 763-6223; E-mail: NATLFX@sprintmail.com; Web site: http://wwwFragileX.org.

7/20-23 Nineteenth Leukodystrophy National Conference

"LOVE AND SCIENCE 2000"

SOUTH POINTE CENTRE, DEKALB, IL

The goal of this conference is to provide the latest information in white matter research and the genetic and clinical manifestations of the leukodystrophies and related disorders. For more information contact the United Leukodystrophy Foundation, 2304 Highland Dr., Sycamore, IL 60178; Phone: (800) 728--5483; Web site: http://www.ulf.org.

7/20-23 Fourth International Symposium on von Hippel-Lindau Disease

"VHL CARE IN THE NEW MILLENNIUM"

MAYO CLINIC, ROCHESTER, MN

This conference, for both parents and professionals, will provide a comprehensive overview and discussion of the latest clinical and research findings on VHL. For more information contact VHL Family Alliance, 171 Clinton Road, Brookline, MA 02445-5815; Phone: (800) 767-4845; Fax: (617) 734-8233; E-mail: info@vhl.org; Web site: http://www.vhl.org/conf2000.

7/21-24 4th International Moebius Syndrome Foundation Conference

STURBRIDGE HOST HOTEL AND CONFERENCE CENTER, STURBRIDGE, MA

Topics will include smile surgery, speech therapy, non-surgical alternatives, genetics research, and social and emotional issues.

For further information contact Sharon Deveney, 5 Copper Ct., Fredricksburg, VA 22406; E-mail: sbdeveney@hotmail.com; Web site: http://www.ciaccess.com/moebius.

Baby Jogger® Essay Contest

Baby Jogger® is having a "Why I Love My Stroller" essay contest. The contest is open to all owners of Baby Jogger strollers. Participants are asked to write an essay related to their strollers (baby pictures may be included). Some of the essays will be published on the Baby Jogger Web site: http://www.babyjogger.com. One winner will be selected and they will receive a decorative quilt. Please mail essays to The Baby Jogger Company, P O Box 2189, Yakima, WA 98907 or send them via E-mail to contest@babyjogger.com. The contest ends September 1, 2000.

continued on page 28

WHY CHILDREN WHO RELY ON GOODNITES ARE MORE INDEPENDENT.

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Circle #60

continued from page 26

Lauren (right), attends her daughter Stephanie's graduation ceremony with husband, Steven (next to Stephanie), and father, Caesar Lacovone.

Loyal Heart Award

Lauren Agoratus, an exceptional parent and EP Editorial Advisory Member, has been awarded the Loyal Heart Award by the New Jersey Coalition on Women and Disabilities, Middlesex County Chapter. In addition to caring for her daughter Stephanie, Lauren devotes countless hours to advocating for the rights of people with disabilities. Her involvement in the disability community includes being a State and Region 2 Coordinator for Family Voices, New Jersey Coordinator for the National Family Caregivers Association, a member of the Family Support Center Advisory Council, coordinator of a support group called Special Parents, and involvement in many more organizations.

Lauren will receive this special caregiver award on Sunday May 7th. Recipients of the Loyal Heart award may be male or female and nominations are made by a person with a disability or community members who have observed caregiving that allows others to achieve their fullest potential. EP is very proud of Lauren's tireless work for people with disabilities. Way to go Lauren!

National Perinatal Foundation Job opportunity

The National Perinatal Foundation is seeking a Senior Development Officer to assume responsibility for implementing the Foundation's Strategic Fundraising Plan. The position includes significant line authority and reports directly to the board of directors through the Chair of the Development Committee. The position offers the option of telecommuting to the Foundation office. Salary and commission are negotiable and dependent on level of experience. Send resumés to the attention of Sheila Sorkin, Executive Director, National Perinatal Association, 3500 E. Fletcher Ave., Ste. 540, Tampa, FL 33613.

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Product Recall Information

- In cooperation with the U.S. Consumer Products Safety Commission (CPSC), Graco Children's Products Inc., of Elverson, PA, is providing new safety restraints for about 7 million infant swings made before November 1997. These new restraints will upgrade older swings. Graco is offering a free, new safety restraint to replace the old restraint system. The safety restraint kit comes with instructions and can be installed easily. It has a buckle that ensures the crotch strap is used each time the waist belt is buckled, so that infants are securely fastened into the swings. Consumers should stop using the swings immediately.

To receive the free safety restraint, consumers should contact Graco Children's Products, Inc., PO Box 100, Elverson, PA 19520; Phone: (800) 934-9082; or Web site: http://www.gracobaby.com/serv/ga3rcal7.htm. Consumers should have the swing in front of them when they call so that Graco can determine if the swing needs the new safety restraint.

- In cooperation with the CPSC, Kmart Corp., of Troy, MI, is voluntarily recalling about 280,000 children's decorative lamps. There have been reports of the lamp short circuiting and catching fire. The "Little Ones" wooden accent lamps being recalled come in six different styles and were sold in Kmart stores nationwide from January 1993 through March 2000. Consumers should immediately unplug the lamps and stop using them. They should return the lamps to their local Kmart for a refund. For further information contact Kmart at (800) 635-6278.

The U.S. Consumer Product Safety Commission protects the public from unreasonable risk of injury or death from 15,000 types of consumer products under the the agency's jurisdiction. To report a dangerous product or product-related injury, and for information on CPSC's fax-on-demand service, call their hotline at (800) 638-2772 or CPSC's teletypewriter at (800) 638-8270. Consumers can obtain this release and recall information at CPSC's Web site: http://www. cpsc.gov. Consumers can report product hazards via E-mail at info@cpsc.gov. ■

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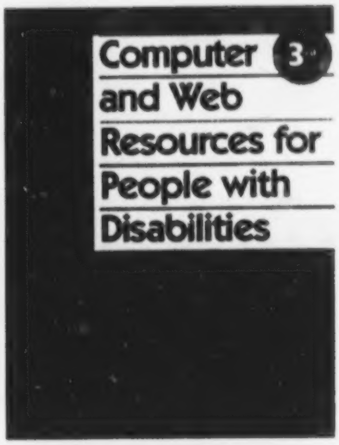
Circle #61



COMPUTER AND WEB RESOURCES FOR PEOPLE WITH DISABILITIES:

A Guide to Exploring Today's Assistive Technology,

3RD EDITION

by The Alliance for Technology Access • Foreword by Stephen Hawking • Publisher: Hunter House, Inc. 2000.
Available through the EP Library:
(800) 535-1910
code: HP30010D
Cost: $20.95 plus shipping and handling

This informative guide offers success stories of technology users, technology tools, product descriptions, and much more. Stephen Hawking writes in the foreword, "This book offers something no other does: a guide to maneuvering the growing world of computers, both the mainstream and the assistive technology, to find what is right for you." The following is excerpted from Chapter 3, "Setting Your Goals."

Identifying your goals

Among your expectations for technology, you can probably categorize your goals into five areas:

1. Education
2. Employment
3. Communication
4. Living more self-sufficiently
5. Recreation

An individual may have technology-related interests in all five areas. In which area or areas do your interests lie? In a specific area of interest to you, what are your immediate goals? Near future goals? Long-term goals? The following sections discuss each area and give examples of immediate, intermediate, and long-term goals.

Education

Technology can help you achieve success from preschool to graduate school.

What are your education goals?

- Full inclusion for your child in your neighborhood elementary school?
- Attending a university and majoring in math?
- Vocational training to help you reenter the workforce?

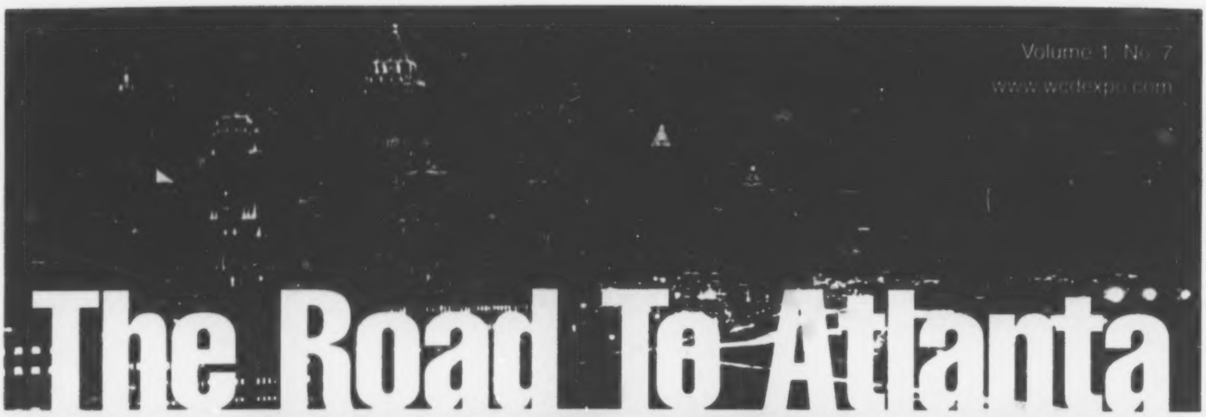
Can you imagine ways in which technology might help you to accomplish those goals?

- Using a computer, could your child complete homework assignments?
- With a low-vision aid, could your child read the same textbook the rest of the class is using?
- Could the computer serve as your pen and paper if you cannot use your hands?
- By using the Internet, could you finally gain access to the research resources of the library which has always been architecturally inaccessible to you?
- Could you use software to simulate your frog dissection?
- Could you read instrumentation if it were magnified or produced audible feedback?
- Could you complete your college education using your computer and the Internet to participate in online courses?

James was a six-year-old with cerebral palsy, and the ultimate goal for him was inclusion. An early step toward this was a simple game—Red Light/Green Light—that involved his entire classroom. Using Ke:nx (Don Johnston, Inc.), a special interface device, we set the computer to alternate between a large square on half of the screen, labeled Red Light, and a square on the other half, labeled Green Light (for more information on Interface Devices and Switches, see Part II). These squares lit up one after the other. When James made his selection by pressing his switch, the computer would say either Red Light or Green Light. The class, assembled in a circle, responded to James' commands by walking or stopping. (In the traditional Red Light/Green Light game, students line up and try to reach the finish line first. The computer version was designed to be noncompetitive so students of all abilities could enjoy it.) The simple game soon had everyone laughing and James was ecstatic. The computer had empowered him as a leader. Red Light/Green Light was particularly successful for James because it was something he really enjoyed doing, it made technology part of the curriculum rather than a separate activity, and there were no wrong answers since the class responded to whatever choice James made.

Education is a lifelong series of learning opportunities, including post-secondary education, continuing education, informal education, self-improvement, and professional development. The common theme in educational endeavors is that an individual acquires and demonstrates new learning. Technology can be used for instruction; for written, artistic, and verbal expression; for reading, calculating, and simulating inaccessible or dangerous activities; for gaining basic reasoning and higher-level thinking skills; and for making the transition from school or from the ranks of the unemployed to the workplace.

Technology can play an important part in your education goals. In a post-secondary program, using assistive technology to earn a degree in architecture might be a long-term goal. A short-term goal might be having an instructor make reasonable accommodations to computer-aided design (CAD) courses, permitting a person with a disability to have access to the technology and materials used by the rest of the class. ■



Volume 1 No. 7
www.wcdexpo.com

The Road To Atlanta

NOVEMBER 10-12, 2000 • WORLD CONGRESS & EXPOSITION ON DISABILITIES

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WORLD CONGRESS & EXPOSITION ON DISABILITIES TO TELECAST LIVE OVER THE WORLD WIDE WEB

Organizers of the first-ever World Congress & Exposition on Disabilities (WCD) have signed an agreement with WeMedia, Inc., the first cross-media company for the estimated 54 million Americans with disabilities, to provide live Webcasting from the WCD floor when the WCD convenes in Atlanta in November. Scheduled for November 10-12 at the disabilities-friendly Georgia International Convention Center, the WCD will bring together for the first time persons with disabilities and special healthcare needs along with physicians and others involved in their care and development.

WeMedia joins WCD's impressive list of media sponsors including Exceptional Parent. Other major supporters include the National Institutes of Health, Emory University and growing numbers of professional and family organizations. The conference portion of this unique event is being produced by the EP Foundation for Education.

In addition to Webcasts of significant programs taking place during the WCD, WeMedia will be promoting the Congress for six months leading up to the event, providing increased advertising and marketing exposure. With some 600,000 to 700,000 visits to the WeMedia site (www.wemedia.com) each month and another 350,000 to that of Exceptional Parent (www.eparent.com), close to 1 million individuals will be receiving information about WCD activities in the months ahead over the Internet.

Cary Fields, president of WeMedia, said his company launched www.wemedia.com as "a one-stop, full-service community dedicated to people with disabilities." He added, "We are very pleased to be associated with the World Congress & Exposition on Disabilities not only because it provides another opportunity for us to bring information to a population that has traditionally been ignored, but also because it is a way to make the general population more aware of the needs and concerns of people with disabilities."

In addition to its comprehensive Website, WeMedia also publishes the award-winning WE magazine and produces other multimedia products including WeDo Internet Radio and WeBroadcast Television. WCD full page, 4-color ads begin running in WE starting with the May/June issue.

The WCD will feature a full conference program that will offer professional participants CME (Continuing Medical Education) and CEU (Continuing Education Units) accreditation. In addition, leaders from the disability community will address important issues specifically related to the needs of people with disabilities, their caregivers and families.

The exhibit floor will feature over 200 companies from pharmaceutical, assistive technology, automotive, personal care and mobility industries, along with those associated with nutrition, communication and publishing. Major corporations, schools and healthcare facilities will be represented at a career fair where people with disabilities, special education teachers and healthcare professionals will be able to discuss job opportunities. And in the WCD Sports Activity Center, the U.S. Disabled Athletes Fund and Special Olympics will present star athletes with disabilities in a variety of sports demonstrations, as well as opportunities for autograph-signing.

For more complete information, visit our Website at www.wcdexpo.com, or call: (877) 923-3976 • (201) 226-1446

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WORLD CONGRESS & EXPOSITION ON DISABILITIES

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ATLANTA • NOV. 10-12, 2000

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Supporting the Motivation to Learn: How Universal Design for Learning™ Can Help

by Anne Meyer, EdD, and Lucinda M. O'Neill

At 13, Pam is artistic and highly imaginative. When she grows up, she wants to be an actress. Five years ago, however, Pam was not nearly so enthusiastic about school. According to her father, the shy, quiet 8-year-old was already behind her younger sister in her ability to express herself. Pam's difficulties went far beyond her shyness or the fact that she spoke English as a second language; she was struggling with a learning disability. At school Pam enjoyed math, but her persistent failures with reading affected both her performance and her self-esteem. Although Pam had supportive parents and teachers, she often felt angry and frustrated about her inability to read and learn from her school's print-based curriculum.

Successful teachers help children think of themselves as "learners" from the first day of instruction. Yet engaging children in learning may be the most challenging aspect of teaching and instructional design. The same task, book, or teaching approach may build competence and confidence in some students while frustrating or boring others.

The reasons students lose their learning spark are as diverse as the students themselves: a creative child, such as Pam, who repeatedly fails to express ideas effectively because of difficulties with written organization and spelling; a child who thrives on exploration and experimentation but is continually required to memorize facts; a child who excels but is given little feedback and encouragement; a child who cannot see any personal relevance in what is being required at school. Regardless of the reason, students who are not engaged in learning are unlikely to progress well.

As we have noted in previous articles, learning is a complex process involving three unique, interconnected systems of the learning brain: recognition, strategy, and affect. Recognition systems recognize patterns, telling us what and where an object is. Strategic systems generate patterns, telling us how to do things. Affective systems determine priorities, telling us which objects are important and interesting. Learning takes place when all three systems are participating. "Though pattern recognition is the first step, a learner must have some strategies for acting on the patterns," explains Dr. Bart Pisha, director of research at CAST, the Center for Applied Special Technology. "The learner must also be engaged in the task—that is, interested and willing to do it. If any of these conditions aren't met, learning breaks down." The role these systems play in learning and how they explain variations among learners guide CAST's concept of Universal Design for Learning™

Children at CAST work together on a computer program. Computer programs offer the flexibility needed to respond to different learning styles.

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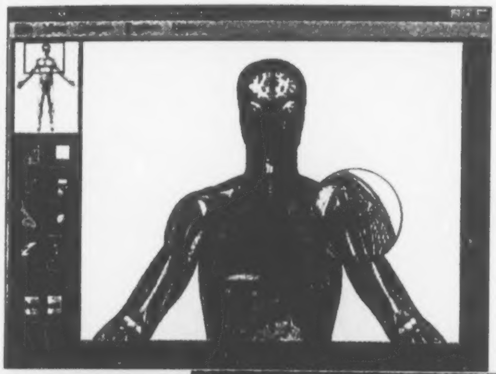

ASSISTIVE TECHNOLOGY Enhances Daily Living Activities

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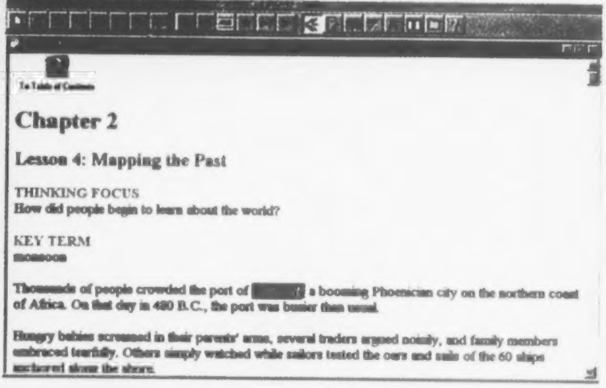
(UDL). UDL is a framework for responding to individual learning differences through the use of technology.

Digital technology furnishes teachers with a way to meet these challenges. The flexibility of digital learning environments, especially those that are "networked," affords nearly limitless opportunity for designing tools and materials that are adjustable to meet a range of learning styles and that will catch and keep the student's attention. Networking to the Internet taps a hugely varied electronic content, which can be evaluated and adjusted by teachers to draw in diverse learners and maintain their interest. The use of computer networks within schools allows teachers to customize their lessons for individual students and to track their progress.

A critical first step, then, is selecting and assembling collections of materials.



Chapter 2

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KEY TERM
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Above: A.D.A.M., the Inside Story, a multi-media program that allows users to learn about the human body by customizing the program. Right, the CAST eReader™. The eReader is an example of a text-to-speech software program, which reads words aloud for the user.

Providing multiple options for engagement

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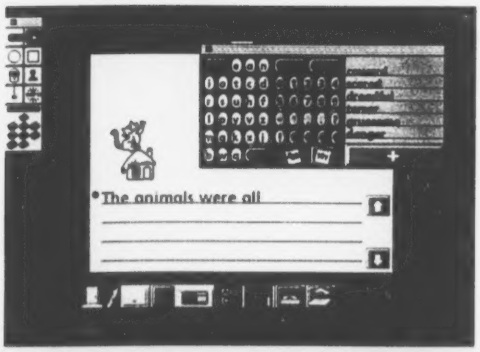
The animals were all

WiggleWorks®, an early literacy program, helps students learn through unstructured activities.

doing. These tools and materials support the motivation to learn by offering multiple ways to engage with the task at hand, thus enabling learners with different preferences and styles to find avenues that suit them. No single program or tool is able to engage all learners. Therefore, it is essential to assemble a variety of materials—software, print materials, and multimedia and online resources—each with as much built-in flexibility as possible. Digital materials offer flexibility by being adjustable in several key areas: structure, level of challenge and support, and content.

Providing different degrees of structure

Pam's teachers sought to engage Pam in learning and to build her confidence in the area of literacy. With this goal in mind, the teachers helped her acquire reading and writing skills with WiggleWorks® (Scholastic Inc.), an early-literacy software program co-developed by CAST and Scholastic. For Pam, the "My Book" area of WiggleWorks was especially motivating. In this section, any one of the 72 children's books presented by the program can be edited, allowing learners to change both the words and the images. Students can experiment with word combinations, erase and replace the illustrations, and hear their new stories read aloud by the computer. There is no time limit for completing activities, and there are no specific directions. Students can always return to the original picture and story with a click of the mouse. For Pam, this supported, exploratory environment was ideal. She was able to place some of her own words in the story (but was not obligated to write and spell every word). She could modify the illustrations while leaving alone the parts she liked. When she completed it, she could print her "new" book to take home and show to her parents, friends, and siblings. While Pam thrives in the relatively unstructured activities of WiggleWorks, other students may need more structure.

Providing the right level of support and challenge

Finding the right levels of support and challenge for each learner is equally important in engaging him or her. If the materials offer the levels of support and challenge needed, the learner can engage and move ahead at his or her own pace.

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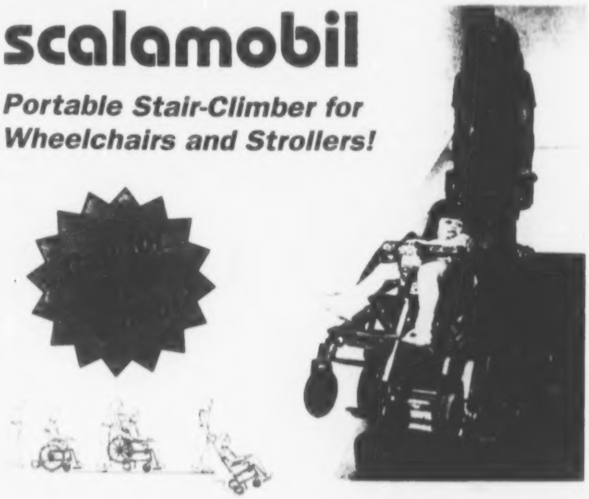

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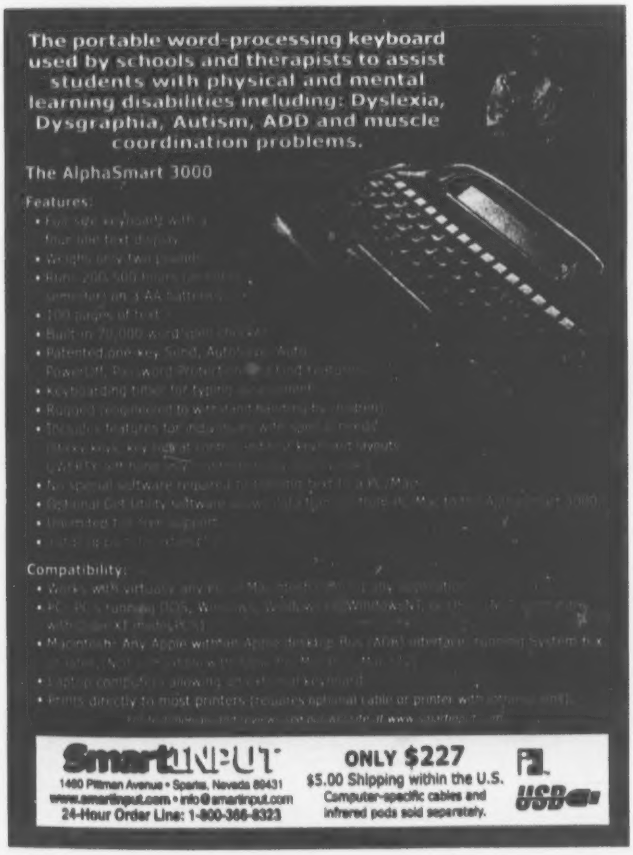
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Materials Considerations

Here are a few things to consider when seeking materials that are adjustable for different students' recognition, strategic, and affective systems:

To support varied recognition systems, look for:
- content that is presented in multiple media, and/or with options for transformation from one medium to another (e.g. text-to-speech);
- adjustable settings such as volume control, size and color of text, highlighting and background colors. These options allow teachers to customize tools and materials to accommodate different learners and teaching goals.

To support varied strategic systems, look for:
- the elements of apprenticeship—models, supported practice, feedback, and opportunities to demonstrate competence—built into the instructional design;
- settings and supports that are adjustable during student practice;
- combinations of tools, software programs and Web sites that provide a varied set of options for practicing, obtaining feedback while working, and demonstrating skills.

To support varied affective systems, look for:
- a range of materials including more and less structure;
- materials that offer adjustable levels of challenge, and supports that can be turned on or off;
- Web sites (which students can access for research) and materials with varied options for content presentation and for content selection.

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The highly engaging nature of video games is in part attributable to the variable levels of challenge, where the level of difficulty is increased in small increments as skills improve. As players master one level, they move to the next, which offers just enough difficulty to keep them from becoming bored. Video games also provide help and other supports that players can call upon if needed.

In a similar way, many software programs offer supports that can be turned on or off, and levels of challenge that can be customized, depending upon the particular student and the particular learning challenge. CAST eReader™, the software program that Pam uses to support her reading as she works on school assignments, is just one example of this type of program. Using eReader, Pam can choose to have text read aloud by the computer or not, depending on the assignment. The text-to-speech option is suitable for use when she is trying to learn social-studies content, but not appropriate when she is working on word decoding (pronouncing words). The text-to-speech feature would undermine this task, offering too much support and no challenge.

Providing multiple choices of content

Exciting a learner's interest in the content being addressed is essential. Depending upon the learning task, content can sometimes be individually tailored to match students' interests and personal identities. If the task is to learn mathematical calcula-

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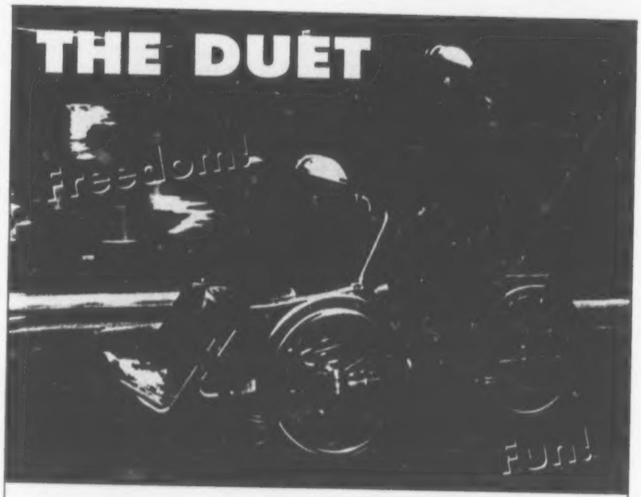
tions, the content used to present math problems could range from baseball to classical music. If the task is to understand the causes of the U.S. Civil War, the content itself is not as flexible, but the way in which the content is approached can be customized for different learners. A.D.A.M., the Inside Story (A.D.A.M. Software, Inc.), for example, focuses on a subject that is relatively fixed: human anatomy. However, the authors offer students flexibility in how the human body is presented in the program, increasing opportunities for learners to relate personally to the content. Learners can customize the body to be male or female, Caucasian or African or Asian, and show genitals or have them hidden behind a fig leaf.

Digital tools and materials can provide the flexibility needed to engage learners of various abilities and keep them motivated as they progress. By assembling collections of such tools and materials in the classroom, teachers can create learning environments that are truly universally designed for learning, offering learners multiple avenues to success. ■

Anne Meyer, EdD, is Co-executive Director of CAST, the not-for-profit Center for Applied Special Technology in Peabody, MA. Lucinda M. O'Neill is a staff writer at CAST. To find out about the tools mentioned in this article and additional resources, visit CAST's Web site at http://www.cast.org/tools.



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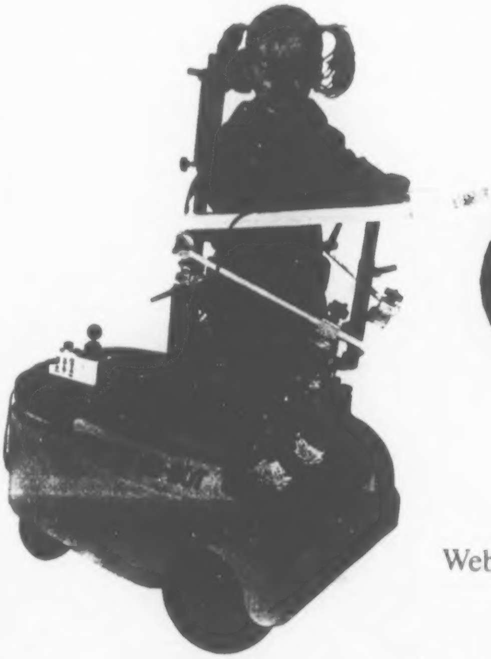

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Circle #42

Katie's Amazing Videoconferencing System

Through state-of-the-art video computer systems, "Truste Kids" and their families can get medical consultations from home at a moment's notice and have fun on the side!

by Vanessa B. Ira

When 9-year-old Katlyn Webb treats guests to a tour of her home in Clifton, New Jersey, they get treated to see a unique sight. Along the way she points out the Beanie Baby collection that she shares with her sister Stephanie, introduces their pet cockatiel, Singy, and ends the tour with the centerpiece of her bedroom—a computer system with a small, digital PC camera perched atop the monitor. Though Katlyn takes pride in demonstrating, with her dad Dave, the cool games and programs on the computer system, she knows that the equipment is more than just a bunch of nifty gadgets. It is part of a videoconferencing network that serves as her 24-hour medical and social connection to the outside world.

Katlyn, called "Katie" by family and friends, has a Chiari malformation and a syrinx. From the time she was born, she has had to live with the effects of that rare condition in which her brain stem has grown into her spinal canal. She has syringomyelia and, as a result of this condition in which a cyst progressively damages the spinal cord, she has constant headaches as well as weakness and pain in her limbs. If left untreated, the chronic crowding of the brainstem and spinal cord can lead to serious consequences, including paralysis.

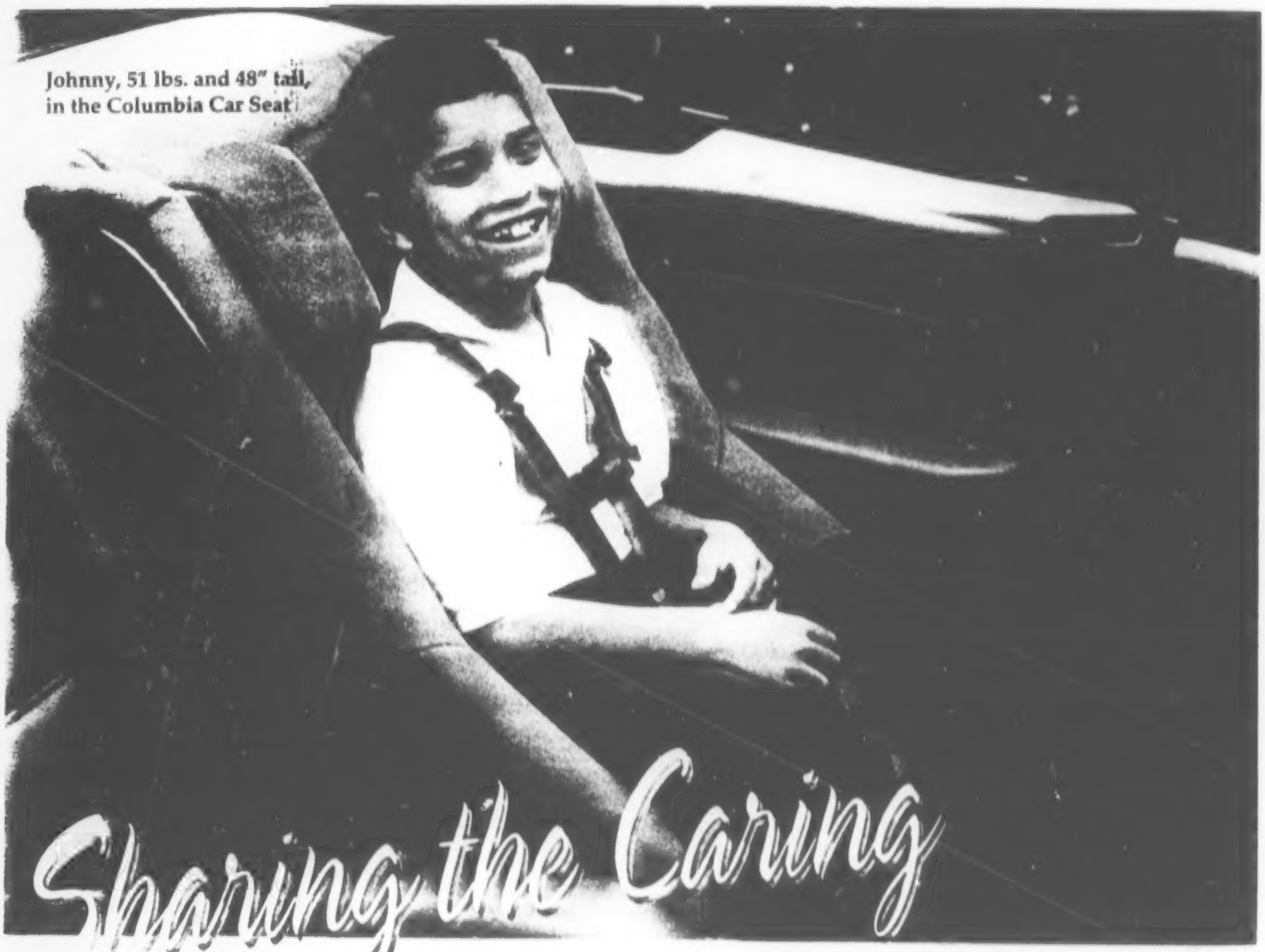
Over an impromptu pizza dinner, the focus of conversations were on Katie's "nth" surgery which would take place in the coming week. Katie, by now a hospital veteran, seemed oblivious to all the talk and concentrated her efforts on entertaining everyone with some music on the family piano. Her mother, Faith, laughs as she relates Katie's experience of being fitted with a halo brace. The halo brace keeps the head and neck in perfect alignment. The halo end is held in place around the head with screws which go through the rim and tighten into the head. "When her doctor needed to make some adjustments, it hurt her so much Katie teased him that if he did it again, she would do the same thing to him!"

Beyond the spunk and humor are the constant care and watchful eyes of every member of the Webb family, which also includes Katie's grandmother, a nurse. Each is well aware of the seriousness of Katie's disorder. In addition to family support and regular trips to Katie's pediatrician, Barry Prystowsky, MD, the family can also receive live medical consultation-at any time of the day or night via the video conferencing system. The entire system was donated by the Children's Emergency Medical Fund of New Jersey, Inc. (CEMF), a 501(c)(3) tax-exempt charitable organization dedicated to helping families of children with special needs requiring 24-

continued on page 42

Katie and her dad, Dave, check out the computer in her room. The computer, complete with videomonitor, connects the family with support systems and with Katie's doctor.

Whether by videolink via computer, or by phone, Fran Reibman, a founder of the Children's Emergency Medical Fund, stays in constant contact with her "Truste Kids."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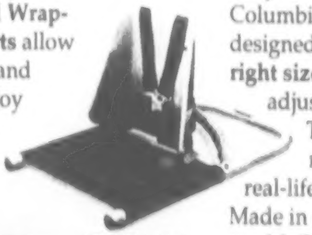

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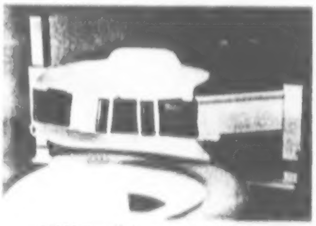

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continued from page 40

hour supervision, who have been cut off from the necessary coverage by insurers.

"When I am really sick, Dr. Barry can see me and I don't have to go to the hospital. This is the best thing," Katie remarks about her videoconferencing system. "The worst thing is during the night, the lights have to be on for Dr. Barry to see me. I love Dr. Barry because he knows how I feel sometimes, and I really hate going to the hospital."

Katie (right) and her sister, Stephanie, share a joke with Fran Reibman (center).

The "Truste Kids"

The CEMF, an affiliate of Quality Physicians Network of America and the New Jersey Pediatric Society, was established in 1998 by Dr. Prystowsky; Fran Reibman, CE, a biomedical/ clinical engineer; and pediatrician Leonard Grossman, MD, and his wife Dora Grossman PhD, Esq. The organization seeks to make services and funds available within a 24-hour period so that, as Reibman puts it, "families can focus their attention on immediate medical issues rather than potential financial burdens. The Fund was established so we can treat, educate and advocate." Reibman explains that only pediatricians and pediatric health care professionals may access the "Truste." However, exceptions are made on a case-by-case basis. "Families just need to contact us and we will take it from there. As a rule, we will verify the child's condition with the family pediatrician," says Reibman. If the CEMF is unable to directly handle the case, a database is accessed and the "Truste" moves the case to the appropriate facility. Besides Katie, some of the other children who have benefited in one way or another from the CEMF's services include: Kristen Smith, who has spinal muscular atrophy and for whom the CEMF was working toward purchasing a power wheelchair; Cory and Chris Dorvil, who both have spastic diplegic cerebral palsy and use wheelchairs; Brent Wood who has aplastic anemia; Deanna Paulov who has a severe seizure disorder (the Fund has underwritten her medications, which were not covered by her insurer); and Jessica Scanniello, who has a rare disorder known as alternating hemiplegia with seizures. The CEMF intervened on behalf of Jessica and her family to assist in straightening out financial obligations.

Katie and her family love being linked up with professionals and other families. Here, Katie shows dad, Fran, and Singy the bird a computer game.

Katie became one of the first "Truste Kids" beneficiaries when the CEMF initiated the program as an experiment in the Winter of 1999. CEMF donated the customized computers, which were equipped with videoconferencing systems and were placed in each Truste Kid's bedroom at home. Some of the "Truste Kids'" stories—Katie's, Kristen's, Deanna's, and Brent's—can be seen on the Web site of the organization. As with many of the things associated with CEMF, their site: http://www. njtrustekids.org, is a piece of work that has come from the good heart of others. Launched in early 2000, it was designed by Nancy Baun, who donated her expertise and efforts to the group. The Web site contains resource links to other disability sites, as well as an entire channel created especially for the children filled with computer games and links to educational resources.

Virtual knocking for emergency or fun

"It is so much fun to talk to Dr. Barry and Fran over the computer," says Katie. "They get to see what I am wearing and I get to see what they are wearing too. When I would be sick very early, every morning, this was the way that Dr. Barry was able to see how I looked—or else he would have had to sleep at my house. I have been able to talk with my aunt. Once I got my computer and video camera, she got one too. This way we can always see each other."

Reibman might be working in her home office when the life-like sound of someone knocking on the door emanates from her PC's speakers. If it is a weekend, the calls are most likely from one of the "Truste" kids, passing on jokes, or giving an update of happenings in their lives. Playful, animated graphical icons pepper the screens of "Truste Kids" and their caregivers, many of them passed on to one another via e-mail. Such are the moments that brighten the days of CEMF caregivers and volunteers who make the lives of chronically ill children less lonely. Explains Reibman: "What we do is set the kids up with our famous knock-knock. They know how to knock-knock me or our other volunteers in the middle of the night, and I know to get up and see what the problem is, what is going on. The fun part is everybody has a code name. Sometimes it's an affectionate name. We want to take the edge off things, we want things that are emotionally rewarding."

The familiar knocking sound can also signal a clinical emergency. Perhaps more important than keeping things on the lighter side is the valuable benefit of round-the-clock monitoring. "The best way to describe the video monitoring in my eyes would be that Dr. Barry became a guardian angel for our family," says Katie's mother. "It has helped keep our family unit together. If it had not been here we would have been constantly running to the office or the ER for care." Each of the "Truste Kids" with a videoconferencing system is hooked up by computer to a network of caregivers who make their managing team: physicians, nurses, and other participating practitioners registered with the Quality Physicians Network,who are linked up via computer at their respective offices or homes. In one instance, when Katie developed an infection from her feeding tube and started to bleed, her mother accessed the managing team through the videoconferencing system.

"It has allowed the doctors to see Katie immediately," says Faith Webb, acknowledging that the immediacy of the system can be invaluable allowing support when frightening episodes occur. "By the time we get her to the doctor's office, symptoms would have subsided, especially with the worst of her situations come at 4 am, or 7 to 8 in the morning with severe vomiting, the blood sugar being up, her heart rate and all that. It is truly an awesome thing, and I am sure that as it progresses, it can only get better for the families as well as the doctors."

Nevertheless, Dr. Prystowsky has cautioned that the technology is not a replacement for in-person consultation. Rather, it can serve as a support system for families with home nurses. The system enables families and doctors to communicate with one another then, just as immediately, chart out a course of action so that no time is wasted as the child is rushed to the hospital in emergency situations. The technology even allows the CEMF to transmit charts, MRIs, and test results prior to the child's arrival at the hospital.

A friend in need

To avoid infections, Katie cannot go out with
friends as often as she would like, and has r
participated in regular schooling for two yea
Through the videoconferencing system, she
still socialize with caregivers and other "Tr
Kids" such as Deanna, who recently had surg
and with whom Katie will be linked to very s
"It has helped Katie because she's been abl
have a friend in her computer and break u
day," says her mother. "We are about to lin
Katie with another "Truste Kid" named Deanna who's just had surgery. That should be an asset for these children because they don't get much in the way of friendship."

The value of Katie having a constant means of communication and of coming face-to-face with her support group through video conferencing cannot be measured. Despite all she has gone through, she remains thoughtful of others and will do things such as spontaneously create drawings for visitors she has met for the first time.

The CEMF newsletter has written of its fondness and devotion to children like Katie: "We call her 'our Katie.' She has come to symbolize what we are about. Rarely is there a night that one of our volunteers is not on the telephone with the family. We have spent countless hours on the telephone (or Internet) with her insurer, the State Departments of Health and Insurance and other State agencies, her specialists in and out of New Jersey, her nurses, her school system, and her family. Thankfully, most of us rarely see a case as complex as Katie's. Sadly, she has also come to symbolize the breakdown in the healthcare system caused by the insurance industry. Through Katie Webb's courage and strength we can find the best in ourselves." ■

For more information about the Children's Emergency Medical Fund of New Jersey, visit their Web site: http://www.njtrustekids.org, or parents and professionals may call (973) 347-8503.

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— R.M., Cleveland, OH

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Circle #67

PART 1

Tech For TOTS™:

Assistive Technology for Infants and Young Children

by Toni Solano, MBA, and Sonia K. Aller, PhD, CCC

Although often overlooked as a benefit to children in this age range, assistive technology (AT) plays an important role in enabling them to develop skills they will need to learn and grow.

The following is taken from the curriculum developed by the Childrens Hospital Los Angeles USC University Affiliated Program. It has been used to train parents and professionals about issues regarding assistive technology for infants and young children.

What is AT? According to the legal definition of assistive technology (in the Individuals with Disabilities Education Act), the purpose of AT is to "increase, maintain, or improve functional capabilities." This can be accomplished through the provision of AT, which directly compensates for an impairment (such as a hearing aid or a walker).

AT can also "increase, maintain, or improve functional capabilities" by giving the child the means to access developmentally appropriate experiences they otherwise would not have because of their disabilities.

Infants and young children may not be regarded as having functions in life that compel the use of assistive technology. For example, nondisabled babies 4 to 8 months of age may bat at a mobile repeatedly. When they first bat, they hit the mobile by accident, and it moves. They notice it moves, they bat purposefully, and eventually cause the mobile to move again. They take this learning, generalize it, and cause other things to move with actions of their bodies. These are the functional capabilities expected at this age, and how higher level functional capabilities are acquired.

What would happen if this child had severe motor impairments? Would this baby be able to bat at the mobile if unable to move her arms? What would the outcome be if we gave the baby with disabilities access to a switch she could operate, with a slight purposeful movement of her head, that would turn on a fan, causing the mobile to move for a brief interval of entertainment?

Why don't more of us think this way?

Assistive technology historically has been regarded as rehabilitative or prosthetic in nature, with the ultimate aim of providing consumers with the means for continued independence and the ability to earn a livelihood. On its face, this contrasts markedly with infants and young children, who are very dependent on their parents and do not earn a livelihood. However, independence and social competence do not arise full-blown at adulthood.

The child's developmental capacity

At birth, infants have very few functional capabilities as we typically think of them. They are completely dependent on their par-

Communicating choices

Tech/Four™
courtesy of
Mayer-Johnson Co.,
(800) 588-4548

Choice-making leads to enhanced decision making, which leads to self-determination. Assistive technology can enable children to make or communicate choices: who they want to hold them, what toy they want to play with, what food they want to eat. They learn from their choice-making and build on their learning, enhancing their ability to make decisions for themselves.

The communication device, a Tech/Four™, speaks the word on the picture when pressed, so others know what choice the child is making.

ents or caregivers. But they are genetically and biologically endowed with developmental capacities in six major domains: cognition, language, gross motor, fine motor, social-emotional, and self-help. These capacities enable the very young to experience their own selves, their environment, and the people in them, and lead to maturation, development, and learning.

Acquisition of individual skills and the development of capacities in each of the domains takes on added importance. This is not just because the capability itself is immediately useful to the child, but because the integration of those skills across domains serves as a foundation that gives rise to higher level competence and independence.

In developmental terms, children who because of their disabilities miss acquiring foundational skills, do not develop a foundation for achieving higher level functions and learning higher level concepts. Furthermore, research shows that in the first decade of life before puberty there are critical times for optimal development of specific types of learning. The implications for assistive technology for infants and young children is clear.

Sensory modulation

Photo by Tumble Forms®. Tumble Forms is a registered trademark of Sammons Preston (800) 323-5547

Interaction with people

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Secondary disabilities

An impairment causes a primary disability which may subsequently impair the child's opportunities for experiential learning. For example, an infant's cerebral palsy may cause an inability to move her arms in a smooth and coordinated fashion. When she attempts to bat at a mobile, she misses it, or hits it on an inconsistent basis. The baby soon tires and gives up. Her purposeful movements do not yield the same results that a nondisabled child would experience.

Furthermore, the chance hitting of the mobile is a precursor to learning through experience that purposeful hitting will cause the mobile to move, a cognitive achievement. In this way, we can see how a motor impairment results in a secondary disability in another domain, in this case the cognitive domain.

Through the use of assistive technology, the child can have access to experiences which lead to acquisition of functional capabilities. Such experiences as **sensory modulation, enhanced interaction with others, interaction with physical environment,** and **choice making** let the child develop skills that give rise to social competence and independence.

Interaction with physical environment

[illegible] physical environment [illegible] of objects and [illegible] a large-handled [illegible] a lipped plate. The [illegible] keep the food on the spoon, which is large enough to allow the child to use a rudimentary grasp. The plate [illegible] which keeps the plate from sliding. In this way the child learns to eat by himself.

Lipped dish and large handled spoon by S&S Worldwide (800) 266-8856

Social competence and independence

The hopes we have for all our children are that they will develop the values and skills needed to become young adults who have acquired the critical capabilities of social competence and self-determination.

continued on page 47

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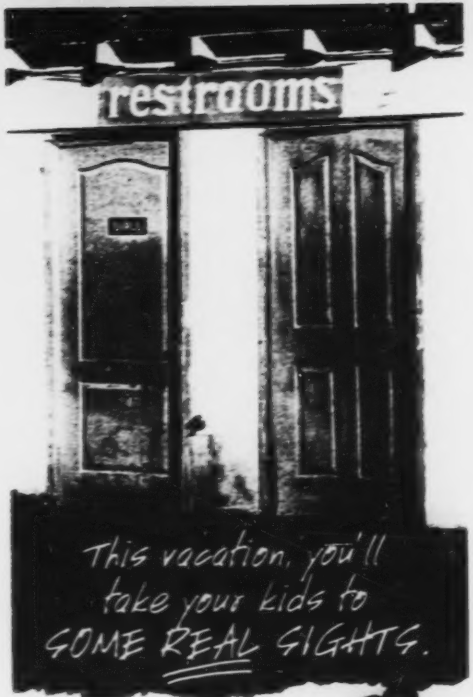

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Circle #53

AT Devices for Young Children

Mobility
- manual and power wheelchairs, various controls
- walkers, strollers
- scooter boards, tricycles

Standing/sitting/lying down
- standers • supported seating

Activities of daily living

- adapted utensils [illegible]
- [illegible]

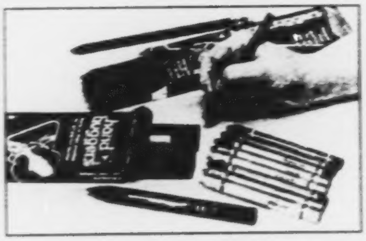
High Back Bath Chair, courtesy of Flaghouse (800) 793-7900

Environmental controls
- to turn lights, TV, and radio on and off

Communication
- picture boards, electronic talkers

Pre-academic activities
- adapted pencils, crayons and markers; grips for writing implements
- slant boards, easels
- adapted scissors
- computers, software, and access devices

Play
- switch-adapted toys
- appropriate off-the-shelf toys
- Dycem (a thin sticky mat to keep things temporarily affixed in place)



Adapted writing utensils: Hand Hugger® markers, S&S Worldwide, (800) 266-8856

Switch-activated toy courtesy of S&S Worldwide (800) 266-8858

Dycem, courtesy of Flaghouse (800) 793-7900

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Social competence arises from meaningful relationships and leads to the fulfilled sense of belonging that allows one to become a member of a family, neighborhood, and cultural community. Self-determination arises from being successful and leads to the judicious decision-making needed for personal identity and integrity. The combination of self-determination and social competence, important determinants of a quality of life, provides the young adult with the critical elements needed to become a self-dependent, autonomous individual and a fulfilled and valued member of an intimate family and social community.

Computer software as AT

Unique features inherent in computers and software make them valuable assistive technologies for cognition and play. These unique features include:

- availability of alternative access devices such as touch screens and switches;
- fast response rate (necessary for children's short attention spans);
- the appeal of multimedia in color, sound, music and animation, self-controlled environment allowing for customizing to the user;
- the non-judgmental quality of software toward its user (it has no bias and no attitude);
- consistency of feedback toward the user.

Taken together, these features allow the child to access a customized environment appropriate to the child's developmental and skill level, where the world waits for him or her and proceeds at a pace set and controlled by the child. In this environment, contingencies can be explored without dire consequences or herculean effort. The child can select a challenge that both piques an interest and encourages mastery and a sense of competence. In this way, the software allows children to access learning experiences previously inaccessible to them because of their disability. ■

Technology holds great promise and benefits for aiding a young child's development. Next month, we continue with a look at how to get assistive technology—the legal requirements and funding resources.

Excerpted with permission from "Tech for Tots™: Assistive Technology for Infants and Young Children (Level 1)

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Circle #38

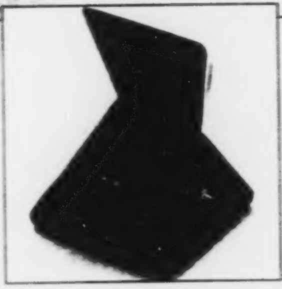
Tech Around the House

Adaptations and assistive devices can help make the livin' easy in and out of the house

by Marilyn Hammond, PhD

Assistive technology can increase your child's independence and quality of life. According to the Rehabilitation Engineering and Assistive Technology Society of North America (RESNA), assistive technology includes devices and services that help children and adults enjoy full inclusion and integration into the community. Assistive devices include: mobility devices like wheelchairs and walkers; large screen computers; electronic devices that make it possible to talk without a voice; assistive listening devices; adapted skis for recreation; and grab bars for toilets and showers.

Thumbs up! Pictured above, a child uses a joystick switch to activate a go cart. Switches allow children with limited mobility to enjoy their toys. Center: A reacher-grabber can help pull up socks on your leg or grab them from behind the dryer. Below: A talking clock, for people with visual impairments.



Assistive devices make it easier to accomplish everyday activities at home. For example, with a reacher, button hook, or zipper pull, your child may be able to get dressed with less assistance. Bathing may be accomplished more independently with a handheld shower, long-handled sponge, shower chair, and/or grab bars.

There are literally thousands of different assistive technology devices in the marketplace today that can aid children and adults in living more independently. An immense variety of equipment already exists, and new devices are continually being developed. Devices can be "high" tech (involving sophisticated electronic components) or "low" tech (relatively simple in construction). Following are some commonly used, mostly low-tech, assistive devices that can help around the house.

Switches

Switches make it possible to control any number of electronic devices. For example, they can be used to operate mobility, communication, environmental control, and recreational or daily living equipment. Switches come in many shapes and sizes with varying sensitivity and durability. Switches can be activated by a variety of movements including blowing into a straw-like device; using a joystick; or by movements of the head, chin, foot, hand, finger, or tongue.

Reaching

An assistive device that is useful in most locations around the home is a reaching aid. It is also great for parents who lose socks behind the dryer or the TV remote control behind the couch.

Vision

To make homes safer for children with visual impairments, white or reflective tape can be used to mark changes in floor levels. Contrasting colors between doorways and walls, as well as the risers and flat surfaces of steps, also helps to maximize vision. Lighted switches are easier for children with vision impairments to find. Furniture moved away from walkways helps aid mobility. Different floor surfaces, such as tile, carpet, and wood, can be used for children who are blind to indicate separate rooms, hallways, and stairs.

There are several devices that can help children who are blind, or with limited vision, function more independently. These devices include talking watches and clocks, magnifiers, and telephones with large numbers. In addition, dial settings for the thermostat, washer and dryer, oven, and microwave can be marked with raised dots or white reflective tape.

Hearing

Carpeting the floors and placing curtains in the windows reduces noise and echoes. Voices can be heard more clearly without distracting noise from other sources.

Some of the many devices available for children and adults who are

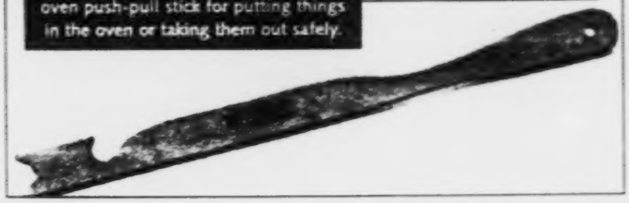
[illegible] with a joystick, for [illegible] arm movement.

A large-number phone [illegible] is helpful for people with [illegible]. The large number pad is helpful for those with poor vision.

deaf or hearing impaired include vibrating personal pager systems, vibrating alarm clocks, telephone amplifiers, telephones with ringers that flash, telecommunication devices for the deaf (TDD), personal listening devices, FM and infra-red systems that transmit and amplify sound, and hearing aids.

Kitchen aids

There are many things that can make eating easier for your child. Food guards that fit around the edge of the plate help keep food on the plate. Plates with suction cups and raised edges also prevent food from sliding and provide stability. Scoop dishes (that are high in back and low in front) with non-skid bottoms may also be helpful. Cups with weighted bottoms are able to stay upright and do not spill. Cups with large handles for easier grasping, one- and two-handle glass holders, no-tip glass holders, and cup holders for wheelchairs are also available. Tumblers with nose cutouts make it possible for your child to drink without tipping back his/her head. Utensils can be purchased or modified with plastic coating, foam tubing, custom molding, adjustable angles, and flexible handles. There are also a variety of leather, cotton, vinyl, and elastic cuffs, clips and straps designed to hold utensils.



Top right: A tumbler with a nose cutout makes it easy to take a drink. Below: An oven push-pull stick for putting things in the oven or taking them out safely.

In order to include your child in meal preparation, other kitchen aids that can help include oven (microwave or regular) push/pull sticks; one-handed peelers, can openers and cutting boards; cutting boards with suction-cups; rocker knives; box, jar, and bag openers; pot holders for stove tops; "lazy susans" in the refrigerator and cupboards; and loop handles on drawers instead of knobs. Many of these items that promote independence can be purchased in local kitchen and restaurant supply stores.

Bathroom devices

There are many devices that can aid with bathroom routines. Long-handled scrub sponges, long-reach toenail scissors, magnifying or one-handed nail clippers, hair brushes with suction cups attached to the base, brushes with Velcro® handles, razor holders, extension combs, toothbrushes with palm size handles, and large toothpaste dispensers may be purchased. Toothbrushes, razors, brushes, and combs can also be modified for better gripping by putting foam curlers or pipe insulation on the handles. They can also be altered by adding a coat of spray-on plastic or vinyl liquid. Single-lever bathroom faucets require less motion and may be easier to use for turning on and off the water. Hair dryers can be mounted on the wall. There are long-handled curved devices to hold and use toilet tissue. Raised toilet seats in a variety of styles often require less effort to sit down and get up.

Portable toilets and add-on bidets attached to water pipes on a standard toilet can be helpful. Chairs made to go in the shower and grab bars that can be

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Left: An adapted comb has a modified handle for easier gripping.
Right: A raised toilet seat for ease in sitting down and getting up.

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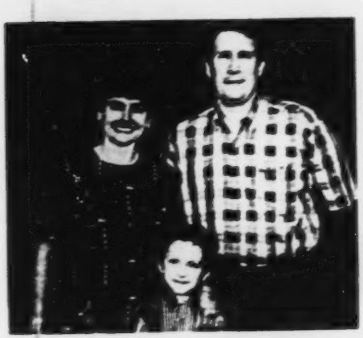
The Simple Things in Life



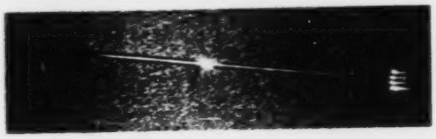
Jeri and Peter Licht with their son Daniel.

Fibrodysplasia ossificans progressiva (FOP) is a rare genetic disorder that causes bone to form in otherwise healthy muscles, tendons, ligaments, and other connective tissues. At birth, children with FOP usually have congenital malformations of the big toes, which are smaller than the other toes, turned inward, and are missing the middle joint. Within the first two decades of life, painful fibrous nodules form over the neck, back, and shoulders that eventually mature into bone. Ultimately, the bone growth creates a second skeleton, encasing the body. As a result, people with FOP experience progressively restrictive movement.

Daniel Licht, of Scarsdale, New York, who will be 6 in July, was diagnosed in 1997 with FOP and is slowly losing mobility in much of his upper body. Besides restrictive movement, Daniel must also take care not to fall or bump too hard into things, because in people with FOP, any trauma to the affected areas—trauma such as a bruise or fall or even surgery to remove the excessive bone—only accelerates new bone formation. "Since his shoulders are frozen, he cannot raise his arms to protect himself," says Daniel's mother, Jeri, who is the director of the Fundraising Committee and a board member of the International Fibrodysplasia Ossificans Progressiva Association (IFOPA). Jeri looks for ways to keep Daniel from injury, while still enabling him to enjoy his life. "We know that nothing can or should prevent a child from being a child."

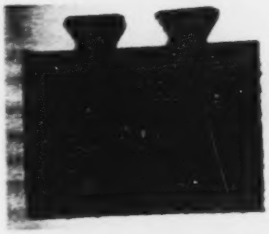
According to Jeri, Daniel's foremost concern at present is finding ways to make doing the everyday things in life easier and playing with his tools, trucks, and friends. Because of limited mobility, Daniel relies on some handy, inexpensive devices that Jeri found can be useful for anyone with limited limb and trunk movement. Following is a sample of the items Jeri describes as useful:

Swivel-Head Spoon—This is a regular short spoon with a swivel head that can be soldered to the end of another long utensil. The spoon bowl can be adjusted separately so that it is level while the handle is at an appropriate angle for the user. For people with weak grasp, spoons with handles that wrap around the hand are also available. Available from Sammons-Preston at (800) 323-5547.

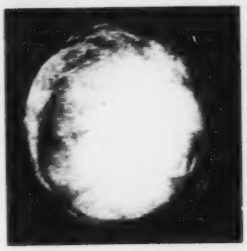


Extendible fork and back scratcher—For people who cannot reach down to their plates to eat, the fork (called "Fork it Over", from Campus Marketing, Sanford, FL) extends up to 25 inches. Besides its obvious use, the back scratcher (log onto Paradigm's Web site: http://www.paradigm-enterprises.com), with a small, attached hand on the end, can be used to move things around when they are beyond someone's reach. Both the fork and scratcher extend like an antenna.) Check your local novelty or joke shop.

Zoo Sticks—These long (approximately 10"), colorful plastic chopsticks with different animals on the end can be used for taking food from a plate and placing it into the mouth. Another use includes picking up small, lightweight items. Zoo Sticks, made by Hog Wild, can be found in toy stores such as Noodle Kidoodle.



Rubberized flooring—You can lay these 2' x 2' x 1" flooring squares anywhere in the house—even to pad the walls—to prevent injury from falling. The pieces fit together like a puzzle and come in all different shapes and colors. The flooring is not slippery when wet, and it makes a good alternative to a rug or carpeting because cleaning is very easy. Shown here is Foam Interlocking Floor Mat by LB International Importers, Inc. Check your nearest home center for availability.



The Swirly Gertie ball—This soft, multi-colored ball has a semi-sticky surface, which makes for easy grabbing. Because it is very soft, it will not cause injury if it hits an unprotected part of the body, even the face. About the size of a soccer ball, the Gertieball can be blown up easily with a straw. For more information, contact Small World Toys, Culver City, CA ; E-mail: Info@SmallWorld-Toys.com.

For more information on FOP, contact:

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Winter Springs, FL 32719-6217
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E-mail: ifopa@vol.com
Web site: http://www.med.upenn.edu/ortho/fop

FOP Resource Center
195 N. Main St.
Boonton, NJ 07005
Phone: (973) 299-8665

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permanently anchored to the wall or attached to the rim of the bathtub aid stability. Handheld and detachable shower heads are available. Nonskid bath mats and bathtub adhesive strips that stick to the bottom of the tub make the surface less slippery. Check the catalogs in the resources list to find most of the above-mentioned items. Some of these items can be purchased in local hardware stores or large discount stores.

A doorknob turner helps people with limited gripping ability turn doorknobs.

Dressing

Clothing styles which are easier to use include front openings, wrap arounds, raglan sleeves, and stretch fabrics. Clothing may be modified by changing a back zipper to the front, or by removing a zipper and replacing it with an equal length of Velcro®. Buttons may also be replaced. Simply remove buttons, stitch holes closed, and stitch strips of Velcro under the flap with buttons and on the flap it faces.

Button hooks, cuff and collar button extenders, dressing sticks, and trouser pulls can be effective dressing aids. Zipper pulls can be purchased or made by attaching a keychain ring, notebook ring, or other type of loop to a zipper tab. A paper clip may be used as a zipper pull.

Twenty-four inch kitchen tongs can be used to pull up pants. Loops of sewing tape can be sewn inside the waistbands of pants to help pull them up. Using elastic thread on buttons adds about an extra quarter inch.

Long shoehorns, bootjacks, and stocking aids make slipping on shoes and stockings easier. Velcro closures on shoes are easier than laces. Elastic shoelaces stay tied and readily stretch open. Shoelace clips can lock laces into place. Clothing aids can be found in the list of catalogs.

Transferring devices

Moving from a chair to a bed can be made easier with adaptive transferring devices. Many different types of devices made for transferring include rotating transfer disks, manual slings, sling seats, stands, belts, boards, and lifts.

A commonly used device is a transfer belt for pivot transfers, which may or may not be used with a transfer board. The belt is put around the child and used as a gripping or handhold device. The transfer board is used to support a child's weight while sliding the child from one position to another. There are several styles available, such as

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boards with slots for gripping, boards with notches to attach to wheelchair arms, and roll-easy transfer boards with rows of hardwood balls, which may require less strength. A transfer bench, which fits halfway in and halfway out of the tub, can serve both as a bath chair and a means of transfer.

Bed rails and overhead trapeze bars aid stability in the bedroom. Secure grab bars by the bathtub, toilet, and bathroom counter also provide support.

A walker like this is an example of an assistive technology device

National assistive technology resources

An excellent place to start looking for information is with the assistive technology coordinator located in Centers for Independent Living across the nation. These coordinators can conduct an evaluation of your assistive technology needs and help you locate equipment and funding. Contact the National Council on Independent Living at (703) 525-3406 (voice); (703) 525-4153 (TDD); or Web site, http://www.ncil.org, to locate the Center nearest you.

To look up assistive technology information, try ABLEDATA. Their huge database of over 17,000 assistive devices can be accessed toll free at (800) 227-0216, or on their Web site at http://www.abledata.com. (See New Products, page 96.)

You may also contact RESNA by telephone at (703) 524-6686, or on the Internet at http://www.resna.org/taproject/at/statecontacts.html for a list of State Assistive Technology Programs funded under the Assistive Technology Act of 1998. These programs may offer assistance in obtaining devices and services, information and referral services, toll-free information numbers, centers where individuals can try out equipment, training, funding guides, equipment exchange and recycling programs, protection and advocacy services, and financial loan programs. All 50 states, the District of Columbia, Puerto Rico, American Samoa, Guam, the Commonwealth of the Northern Mariana Islands, and the U.S. Virgin Islands have Tech Act Projects.

Take advantage of what's out there

There are many national and local resources available to help you find the assistive technology devices your child needs. Assistive devices and services do not have to involve cutting-edge technology to provide the support a child with a disability needs in carrying out daily living activities. Ask your child's physical or occupational therapist or teacher for suggestions

Resources and Catalogs

Switches
ABLEDATA
(800) 277-0216; Web site: http://www.abledata.com
AbleNet, Inc.
(800) 322-0956; Web site: http://www.ablenetinc.com
Adaptivation
(800) 723-2783; Web site:
http://www.adaptivation.com
Zygo Industries, Inc. (503) 684-6006

Adaptive clothing and dressing aids
Adaptability products for independent living (800) 243-9232

Dressing/Grooming Aids
JC Penney Special Needs Catalog (800) 222-6161
Casual to formal clothing

M & M HealthCare Apparel Co. (800) 221-8929
Stay-dry (incontinence) fashions, clothing

Sammons-Preston (800) 323-5547
Aids to daily living, rehabilitation equipment, clinical supplies, communication, vision, pediatrics, evaluation, orthopedics, and more

Sears Home Healthcare (800) 326-1750
and (800) 733-4833 (TDD)
Modified clothing

Daily living, communication, rehabilitation, orthopedics, vision, and hearing devices
Ableware (973) 628-7600
Personal gadgets with pictures and descriptions

American Printing House for the Blind
(800) 223-1839
Supplies for individuals who are blind

Hear More (516) 752-0738 and (800) 881-4327
Devices for people who are deaf or hearing impaired

North Coast Medical ADL Catalog (800) 821-9319
Products for daily living activities

The Lighthouse Catalog (800) 829-0500
Devices for people with impaired vision

LS&S (800) 468-4789
Products specifically for individuals who are visually or hearing impaired

Radio Shack (800) 843-7422
Electronic devices and resources

Smith & Nephew (800) 558-8633
Rehabilitation aids

S&S Adaptability (800) 266-8856
Products for daily living and rehabilitation therapy

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Marilyn Hammond, PhD, is the Instructional Design Specialist for the Utah Assistive Technology Program at Utah State University.

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Circle #18

Elise Gets Assistive Technology

by Theresa Rebhorn

Elise Rebhorn (r.) and her best friend from school, Sarah Borgatti, share a joke with the help of Elise's communication device.

Elise got her first wheelchair when she was 3. It was nothing fancy, but it fit her and she was comfortable in it. Until she was 9, we wondered and asked about the possibility of Elise being able to use a power chair. Elise has cerebral palsy and spastic quadriparesis. She can move somewhat, but most of her body does not work well and she cannot speak. We were told that she did not have consistent control over any single body part that would enable her to drive on her own. Since this seemed to be the case, we did not question it, and besides, a higher priority was finding a communication device that Elise could really use.

We had tried low-tech and high-tech strategies for communication, but nothing seemed to be a good match. Too much effort was required on Elise's part and the output was usually insignificant. Luckily, as any parent knows, a lot can be communicated with just yes and no. As she got older, though, yes/no wasn't cutting it. Elise had things in her head she wanted to get out and could not. It also became increasingly difficult for her to do school work without access to communication or a computer.

Going for the evaluation

I had heard from friends about the Kennedy Krieger Institute in Baltimore, Maryland, which does assistive technology evaluations. They spoke highly of the quality and caring of the Institute staff. I decided to make an appointment for Elise to be evaluated for communication and, just for the heck of it, power mobility. I wish now that I had not waited.

The team assembled for the evaluation included a speech pathologist, OT, PT, and rehab equipment specialist. First they looked at communication, asked lots of questions about what we had tried, the different methods of access Elise had used, and how she communicated (eye pointing, vocalizing, some word approximations, smiles for yes, frown/pout for no and crying, when all else failed). They assessed what Elise could get her body to do, asking her to do things: "Elise, try to hit my hand with your head, hand, elbow, knee, foot, etc." In short order, they determined that she could pretty consistently hit a switch with her left foot. Then the REALLY fun part began. They brought out an electronic communication device and showed Elise what it could do. Both the assessment techniques and the device were brilliant in there simplicity. The device had six large buttons, each of which played recorded messages when activated. One button asked, "Can I play with a doll?" and of course, there was a doll for Elise to see and touch. When Elise realized that SHE could ask for (and get) what she wanted by hitting the switch with her foot, she wasted no time at all in consistently and constantly asking for the doll. She laughed her head off at getting a roomful of adults to meet her demands. Even more exciting for me was to discover that Elise has a remarkable talent to quickly remember and access where different messages were programmed.

I was so amazed at how much this team was able to discover about Elise, after hearing the words "I don't think so" from others. By lunchtime we had put together a comprehensive list to request funding for the

Elise in her little, blue wheelchair, before she got assistive technology device and customized switch access. Then it was time to look at power chair options for Elise. In about an hour, a power chair was rigged to fit her decently and a switch-activated driving system was set up in the head pads. In the hallway, Elise was shown how the chair works (head up against the center pad to go forward, move off it to stop, etc.). The team and I positioned ourselves 20 feet in front of her and said, "Go!"

With some hesitant starts and stops, Elise started moving. The look of amazement, surprise, and delight on her face is forever burned into my brain. I know what she's thinking. "Hey, I'm doing this! I'm moving!" She didn't stop for 45 minutes. She was soaked in sweat and wanted to do more. The only way she would agree to leave was with the promise and a date set for a follow up appointment and even then she burst into tears. We were exhausted—and we were also exhilarated.

Subsequent appointments allowed us to fine tune what Elise would need in a power chair of her own. Experience has taught us that her use of AT is not set in stone. Some days she drives great; some days she tends to go in circles. Some days she goes in circles on purpose. She does most of her driving at school since our home is not accessible, and she has the greatest fun using her chair in PE, chasing kids and adults who just egg her on.

Her use of the communication device has been dramatic. The first hurdle was of my own making, figuring out what to program that Elise wanted or needed to say. I found expert guidance from Kennedy-Krieger and from another experienced mom whom I met at the Symposium on Literacy and Disabilities. The Symposium, directed by the Speech and Hearing Sciences Department of the University of North Carolina—Chapel Hill, is a meeting of individuals—researchers, educators, parents, therapists, people with disabilities, policy makers—concerned with advancing literacy for people with disabilities. (See Resources for more information.) The breakthrough came when I created recordings on the device for her to access at Christmas, enabling Elise to say "Merry Christmas," ask to sing specific songs, and say "Thank you" and "You're welcome" for gifts. The other big hit was programming some jokes for Elise to tell.

If I knew then about AT what I know now...

- I would not have waited so long to have Elise evaluated for AT. If you think your child can use AT, keep asking your PT, OT, and SL/P. To find an AT evaluation source, ask your child's pediatrician and/or developmental pediatrician, children's hospitals, rehab. hospitals, or equipment vendors.
- I would not have gotten so frustrated had I understood that insurance companies often turn down a request at least once. (I learned to appeal as many times as was necessary, getting additional documentation to support each request.) Also, the professional team also helped. They were far more versed in submitting requests for funding for AT than I ever want to be.
- I would have taken Elise back more often for re-evaluation because kids and technology change.

Now that Elise is a teenager and in middle school, her vocabulary has expanded to a slew of academic stuff and the really important things teenagers love to say: "Whuz up?" "Don't bug me."; "Can you come over after school?"; "Mom, come here, I need you"; "Can we go shopping?" Elise's best friend from school is thrilled that she has her very own message area on Elise's communicator so they can talk to each other. Now, of course, her other friends want their own area, too. And, they are really jealous that Elise can drive at a much earlier age than they can!

Elise's gaining mastery of AT will be a lifelong endeavor. I learned that other parents and their children who use the devices have been the best resources. However, the going is SLOW. The challenge is not the device, but figuring out how to take something "unnatural," like a communication device, and make it part of Elise's life in a "natural" way. It is a great deal of work for her and for me (programming and using the device), but we know the power it holds for her, and now there is no turning back.

My daughter is now a maturing young lady—who has wheels, has a voice, has friends and has a life that is so much fuller because of what she can do thanks to assistive technology. We can hardly wait to see what the next ten years will bring. ■

Adapted from an article that originally appeared on the the Family Center on Technology and Disability Web site: http://ucpa.ucp.org/fctd.

Theresa Rebhorn works for the Academy for Educational Development (AED) contributing to the work of the National Information Center for Children and Youth with Disabilities (NICHCY) and the Families and Advocates Partnership for Education (FAPE) project, as well as other disability related projects for AED. The Rebhorns, Theresa, Elise, dad Chuck, and brother Brian, live in Fairfax, VA.

Resources

For more information on AT and referrals, contact:

Kennedy Kreiger Institute
Phone: (888) 554-2080 (at the message menu, push 1 on the dial pad)
Web site:
http://www.kennedykrieger.org

The Alliance for Technology Access
Phone: (415) 455-4575
Web site: http://www.ATAccess.org

Augmentative Communication Meetings
Symposium on Literacy and Disability
Web site:
http://www.alliedhealth.unc.edu/lit2k

Summer Seminar on Literacy in Augmentative and Alternative Communication
The course is appropriate for parents and professionals attempting to support literacy learning in children or adults using augmentative and alternative communication (AAC). Web site: http://www.gac.edu/~dkoppenh/summerseminar/info.html.

Technology Breaks Down Barriers

Teleconferencing helps parents and professionals integrating children with acquired brain injury into the classroom

by Louise Kinross

Brad (right), who returned to school following an acquired brain injury (ABI), performs a science experiment on electrical currents with one of his teachers. With the help of the team from Bloorview MacMillan Centre, Brad's teachers have been getting support and education to help him successfully reintegrate.

When Brad returned to high school following an acquired brain injury (ABI), among the greatest challenges he faced were teachers who did not understand the depth of his new disability.

They thought he was exactly the same as before his accident," recalls his mother, Linda. "So when Brad would completely forget a homework assignment, or couldn't understand the assignment, the teachers assumed it was a behavioral issue. They didn't see how cognitively different he was."

Teachers at Brad's school in Ontario, Canada, remembered Brad as a promising athlete and a bright and popular 15-year-old who breezed through school with little effort and a lot of attitude. But as the result of an accident in which he was hit with a baseball, Brad had a brain injury that left him with significant memory, concentration, and processing problems. "He had trouble comprehending what he was reading, and wouldn't remember a page by the time he was onto the next," Linda says.

ABI—which can be caused by a physical trauma, stroke, or tumor—is the most common cause of acquired disability in children in North America. According to the Center for Disease Control, about 600,000 children sustain traumatic brain injuries in the U.S. each year. Up to a quarter of these will have severe, life long disabilities, and this group is growing as medical advances increase trauma survival rates.

The education system has been challenged to respond to the unique learning issues presented by children with ABI. While U.S. studies show about 70 percent of high school students with severe brain injuries drop out or experience failure when they return to their home schools, many do not recognize ABI as a disability. Additionally, few special education teachers have training in the effects of ABI, and courses to educate them on ABI are scarce.

"ABI is often a 'hidden' disability," says Pamela Speed, an ABI educational consultant at Bloorview MacMillan Centre, Ontario's largest rehabilitation facility for children with disabilities. "Physically, the kids recover for the most part, and even the experienced classroom teacher may not initially see the depth of the deficits."

Speed and a research team at Bloorview MacMillan have set out to change that misperception. Last year, they developed the world's first online course on the educational impacts of brain injury called "ABI: Integrating Students in the Classroom." The three-week introductory course, targeted to teachers, therapists, and parents, provides an overview of the unique educational needs of children with ABI, and, through assignments and an interactive bulletin board, gets participants looking at practical strategies for addressing them in the classroom.

On course for success

The course starts out as basic as it gets in terms of 'What is a brain injury?', and then becomes highly sophisticated because of the multidisciplinary brain-storming that happens on the bulletin board," says Chris Brown, director of Bartimaeus Rehabilitation Support Service, who took the course last year. Brown's Toronto agency provides child and youth workers to support students with ABI in the classroom. "You have professionals from all parts of the world posting messages about real-life cases (without identifying the individuals) they are working on, and helping each other problem-solve. So the course goes beyond the theoretical and becomes like a practicum in terms of the interaction it generates."

Speed says the goal of the course is to help participants "accurately identify the more subtle and hidden deficits students with ABI experience, so that they can intervene in effective ways."

For example, a student with ABI may have intact intelligence, but severe problems with attention, memory, and the ability to process information. "Teachers are often perplexed because there will be a huge discrepancy between what the child appears to understand in class, and how she performs on a related assignment or test," Speed says. This is because skills that came naturally to the student prior to the injury—such as organization and problem-solving—are now gone. As a result, "the child may hand in incomplete homework, lose assignments, or be unable to stay on task," Speed says. "The teacher often assumes there's a lack of motivation, when in fact, the student is putting forth 200 percent in terms of the effort required to focus and process information, but can only come up with 50 percent on tests and assignments."

In addition to losing certain cognitive skills, students with ABI may have trouble performing more than one skill at the same time. "For example, to process a lesson from the teacher, you need to be able to switch your attention from the blackboard to your notes, store something in working memory, and reason with the information to understand it," Speed says. "The head injury slows these processes down or causes the student to lose focus and get lost."

What makes children with ABI different from other children with learning disabilities is the global nature of the disability. "It's the interconnection of the deficits that a child with a serious head injury has—problems with attention, memory, slowness in thinking—that makes them unique," says Glenda Hymus, an ABI educational consultant who works with Speed on the research project at Bloorview MacMillan.

Geb Verburg and Pamela Speed view the home page of the ABI online course. The videoconferencing capability appears in a window on the upper right corner of the computer screen. Shown in the window is another member of the team, Blythe Brett, research assistant.

This was brought home by teachers who took Bloorview MacMillan's online course early in their work with students with ABI. "Eighteen years of teaching have not prepared me for the special challenges these (students) are facing," wrote a 5th grade teacher from British Columbia, as she introduced herself on the bulletin board. The teacher had two students with ABI in a regular class of 30. "The most frustrating part for the three of us is that for both boys, some days things are going along just great, and the next day they seem to have forgotten everything they have learned and more."

In addition to significant learning challenges, the child with a brain injury also has to cope with the frustration of remembering how easily she once accomplished school tasks. "Students with ABI are very aware that the way they learn is (very) different from before their injury and are experiencing a sense of loss," noted a counselor of ABI students on the online bulletin board. Brad admits that the hardest thing for him since returning to high school has been "trying to live up to my own expectations."

Educational strategies

Bloorview MacMillan's course outlines strategies to help students with ABI be successful. "These focus on structuring the environment so that the skills that were once automatic to the child are now prompted externally," Speed says. For example, the teacher who is giving a lesson needs to cue a student to the different components of the lesson: "This is the topic; these are the five key points; this is the supporting information; these are the assignment instructions." Information on how to complete an assignment needs to be broken down step by step. Each task needs to be demonstrated until the student learns how to initiate them independently.

Other strategies for working with students with ABI include slowing the pace and content of instruction, using a variety of mediums to present the information (including visual and hands-on) and repetition. "Today's classroom teachers have a curriculum to deliver and it goes at the speed of lightning," Hymus says. "We recommend small group instruction where the pace can be slowed and concepts can be repeated, reviewed, and drilled." Most students with ABI

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Videoconferencing: the classroom as testing ground

Videoconferencing technology was recently placed in the classes of two Ontario students who are being reintegrated into their regular schools following acquired brain injury (ABI).

The pilot project, developed by an ABI research team at Bloorview MacMillan Centre, provides teachers with instant support from ABI education specialists at the rehabilitation facility, whenever they need it. "The idea is to be able to address problems as they arise, on the spot, without teachers having to wait three weeks for a meeting with us," explains Glenda Hymus. "The project also gives students contact with the rehabilitation team they've grown close to during their recovery."

Glenda Hymus and Pamela Speed follow a caseload of 250 students who are returning to school throughout the Greater Toronto Area. Many of these students' teachers have never worked with a child with ABI, and have little training in how to meet their unique educational needs. Yet because of the size of their caseload, Hymus and Speed cannot physically travel to each school on a timely basis. Computer-based videoconferencing was seen as a way to provide immediate support.

The technology was set up in the resource rooms at each of the students' schools. It allows live, face-to-face contact with Hymus, Speed, and other specialists at Bloorview MacMillan, so that the student, teacher, and specialists can problem-solve about any learning issues. By transferring images and files, and sharing files, students can show the consultants any work that is giving them difficulty. "For example, you can work on a math problem together," Hymus says. "You can see what the student is doing, and they can see what you are doing."

In implementing any new technology, this use of videoconferencing has met with challenges. Technically, the videoconferencing relies on integrated services digital network (ISDN) telephone lines, which are costly (about $100 a month), and not universally available. This has made videoconferencing difficult to implement in some areas.

There have also been social barriers. One student, who said he enjoyed using the technology, objected to going to the resource room where it was housed. Prior to his injury he had never used this room, and he felt out of place there.

"It sets the student apart from everyone else, but at the same time it gives them a special tool," says Geb Verburg. "It can be a positive or negative experience, depending on how it is implemented into the student's day."

There have also been challenges in getting teachers to use videoconferencing. "It's not part of the teacher's culture to say, 'let me call this person and get a quick consult' in the middle of the class," Verburg says. In addition, the technology takes time to learn and use—a rare commodity for today's teachers. "The big issue we had was that the teachers were too busy," Hymus says. "In a resource room, they had many students to work with, and it was time-consuming to use the videoconferencing for just one student."

Despite obstacles, technology's rapid growth and improvement should make its use easier and more commonplace. For now, the teachers and students who continue to work with the technology will be blazing new trails, meeting the challenges, and reaping the rewards.

Videoconferencing may have a future role in the regular classroom, alongside the Internet. "But it would probably require a very different attitude and work pattern on the part of the teachers and students," Verburg says. "Nothing less than a metamorphosis of classroom culture is required: from a classroom that is a cocoon to a classroom that is wired to the world and has students and teachers who dare to step out of the classroom virtually and find out what is happening elsewhere."

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need to take a reduced courseload when they return to school.

Brown says the strategies covered in the online course took on real-life application on the moderated bulletin board, where questions and case histories were posted and a lively dialog was struck by faculty and participants. "People would get on the bulletin board and say, 'I'm working with a 12-year-old boy in my class and he has difficulty with this, and I've tried this and that. Does anyone have any ideas?' Often, students with ABI are challenging and the answer isn't black and white. It's helpful to exchange ideas and experiences. The course was suitable for professionals at different levels of understanding and experience."

Support for parents as well as professionals

The online course has provided an efficient way to share information on ABI with educators, therapists, and parents worldwide. "It was initially targeted to teachers, but we also have registered nurses, physiotherapists, speech therapists, occupational therapists and parents," says Blythe Brett, a research assistant with the project. Participants logged on from Australia, Sweden, Greece, Germany, England, the United States, and Canada.

Response to the introductory course has been so positive that eight new, more advanced courses—focusing on the learning, social, emotional, and behavioral effects of ABI—are being developed. Plans are also in the works to formalize the course as an accredited university program. "We also hope to put in place some online support structures, where educators and parents can help solve each other's problems and students can share support," says Geb Verburg, a cognitive scientist at Bloorview MacMillan and coordinator of the project. Currently, the bulletin board is only active when the course runs, but in the future it may be possible to build an ongoing listserv for educators and parents, and a separate Web site where students with ABI can share practical advice and support.

The next introductory course will run when registration reaches 50 participants. You can register by visiting http://snow.utoronto.ca. The "Professional Development" header will bring visitors to a page containing the list of courses.

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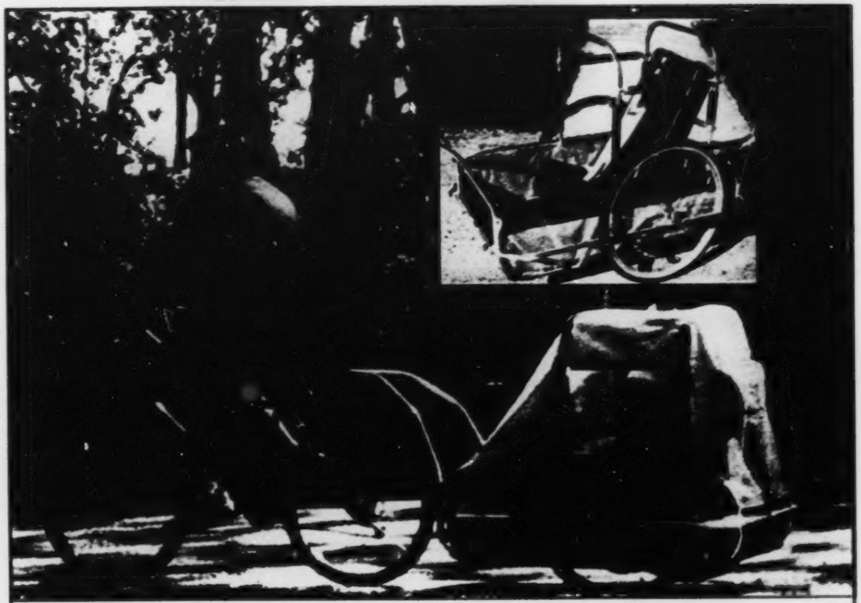

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You can view the course, which is not currently running, by visiting http://snow.utoronto.ca:1800. Choose "SNOW courses" from the category and "Acquired Brain Injury" will be one of the courses listed. Simply type in "guest" when asked for your password.

"ABI: Integrating Students in the Classroom" was made possible by funding from the Ontario Neurotrauma Foundation, the Office of Learning Technologies of Human Resources Development—Canada, and Bloorview Children's Hospital Foundation. The project also received support from the Special Needs Opportunity Window at the University of Toronto, and Cambrian College of Applied Arts and Technology in Sudbury, Ontario, Canada. ■

Louise Kinross is the Communications Coordinator in Family and Community Relations at Bloorview MacMillan.

The following resources on brain injury will interest educators, parents, and therapists:

Brain Injury Association
Includes medical and educational information, and a list of American rehabilitation services by state.
http://www.biausa.org/

"How can I work with the school?"—(A 'how-to' on the parents' role in working with the school to reintegrate their child following brain injury).
Written by a parent and located on the Brain Injury Association of Minnesota Web site.
http://www.braininjurymm.org/parent.html

Neuroscience for Kids
A great Web site on the brain and brain injury, targeted to students of all ages. Includes classroom activities that can be used to help prepare other students when a child with a brain injury is returning.
http://weber.u.washington.edu/~chudler/interr.html

Think First
An American brain and spinal-cord-injury prevention program. Includes a curriculum for elementary school students grades 1-3, and kid-friendly games and activities.
http://www.thinkfirst.org/think1.htm

National Resource Centre for Traumatic Brain Injury
Includes educational materials and frequently-asked questions.
http://www.neuro.pmr.vcu.edu/

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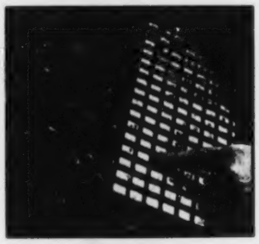

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A Proactive Role for Parents in IEPs

Changes and implementation in Individualized Education Plans (IEPs) from one school to another are difficult. Parents need to be proactive to help classroom teachers meet the needs of secondary school students who qualify for special accommodations.

by Kathleen M. McCoy, PhD

For students eligible for special education services, each change of schools requires orchestration between the members of the current IEP team with members of the next IEP team. Students and their parents are the only members of the IEP team that remain constant across all school settings and levels. This unique role is not to suggest that parents assume instructional responsibilities for their children, but rather that parents and students become more involved in the communication process with the teachers.

The success of students with disabilities transitioning to high school is dependent on the role of their parents as active advocates. High school is a much more complex environment for young people and parents to navigate than the earlier grades. It usually has a larger student population and may even be further away from home than the middle school. The teachers are specialists in their subjects and have the added responsibility of extracurricular activities to constrain their time. They may have little regular contact and communication with other teachers. As a result, they may not fully understand the behavior and learning style of students with disabilities. The organization of the IEP teams is different and sharing information between the schools can be very difficult. The special education teacher, no matter how willing, simply cannot physically meet on a regular basis with all the teachers who instruct the student.

These issues became apparent when my daughter, Elizabeth advanced to high school. With the cooperation of school personnel, I developed a method of dealing with the difficulties and a **Daily Progress Report** that may be useful to other parents. I adapted the standard progress form used in her school. You may want to adapt the form used in your child's high school.

Elizabeth's story

For several years, I had noticed that Elizabeth was having difficulty in school. She often did not complete tasks or took an excessive amount of time to finish work especially if the activity required writing and spelling. For the most part, I as a parent could provide the educational instruction she was missing. By junior high, however, the school demands were too great for us to compensate with supplemental home instruction. Armed with writing samples and letters describing work habits written by her previous teachers, I referred her for evaluation in special education when she was in eighth grade. As a result, Elizabeth was classified as having a learning disability.

For Elizabeth, note taking and completion of lengthy essay questions were not possible, nor was reading long passages from a text. In addition, she had developed poor work habits, i.e., not completing assignments in class or keeping track of homework.

Fortunately, the number of students in Elizabeth's middle school was small. Each grade was taught by teams of teachers with one special education teacher assigned to each team. The team members interacted on a regular basis and shared information about each child. The high school had a much larger student body, classroom teachers who acted independent of each other, and a small special education staff.

In mid April, a meeting was set up for the IEP team of the middle school and special education personnel of the high school. When the IEP team arrived from the high school district, they lacked one essential element—the classroom teachers. Through discussion, the group agreed that Elizabeth would be included in all classes. No formal IEP could be written, however, without the presence of the classroom teachers who would not be identified until mid June. The first day of high school was in mid July. The special education staff had intended to hold an IEP meeting the day before school started, but the timing was not realistic.

Problem solving

To meet Elizabeth's needs and the needs of the general education teachers, an intermediary step was needed before the IEP meeting. It was important for the classroom teachers to observe Elizabeth's performance in the classes they taught at the high school. This led me to develop a "Communication System" that proved to be a useful means of maintaining contact among all members of the IEP team. The model Communication System ultimately proved to be a highly successful means of contact among all members of the IEP team. An outline for the Communication System is presented in Table 1 on the following page.

Pre-IEP meeting: Before a meaningful IEP meeting can take place, the classroom teaching staff needs a basis for decision making. They need to get to know the student and how the student performs in their settings. They need to know who the student is and what behaviors to expect.

Introduction by the special education teacher: The special education teacher needs to notify each of the classroom teachers that a student with special needs will be attending class. At the beginning of the first semester or quarter in high school, the special education teacher knows the student only as described through previous IEPs; only a partial image of the student is available. The parents, or the student, need to complete the picture.

Introductory letter: The parent or student should send an introductory letter to each teacher. This letter should be brief—a page or less. The beginning

continued on page 64

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Table 1. Outline for a Communication System at the High School Level

Part 1: Pre-IEP meeting

- a. Special education teacher meets with classroom teachers
- b. Letter of Introduction from parents
- c. Parent(s) have brief meeting with each classroom instructor to establish communication process, i.e., set up communication log
- c. Refinement of communication log based on the needs of each instructor

Part 2: IEP meeting

- a. Input from teachers
- b. Consensus for IEP

Part 3: Semester progress

- a. Utilization of communication log
- b. Special education follow up as needed

Part 4: Begin cycle again for new teachers the following year

continued from page 62

of a school year is hectic, and most teachers do not have the time to read and digest massive tomes. The content of the letter should explain the behavioral manifestation of the student's problem. Many teachers are not familiar with special education vocabulary or classifications. They can underestimate or overestimate the impact of the disability on students' performance. A description of Elizabeth's situation was as follows:

> *Certain instructional accommodations are necessary and have been defined in her IEP. Elizabeth has no cognitive or emotional problems. Elizabeth has fine motor issues with eye-hand coordination, near and far point vision, manuscript, and visual motor memory. In essence, she cannot write, copy from a board or a book, or read for more than a few minutes without undue fatigue. When she is overly fatigued her concentration is lessened, and she sometimes misses class requirements.*

The behavioral description is followed by a short list of the types of accommodations that have worked in previous classes; these accommodations are also presented in classroom terms. By identifying classroom activities, the classroom teacher is not overwhelmed or led to think that special training is needed to work with the student. The classroom teacher can assume responsibility for providing the accommodations because the accommodations are well within their instructional expertise. The necessary accommodations are listed in bullet form in the letter to make them stand out:

- give extra time during essay tests, in class writing, and reading assignments
- allow highlighting rather than copying important information
- allow use of tape recorder when possible
- use homework log on daily basis to keep track of assignments

In the conclusion of the letter, the teachers are asked to observe the student's behavior until an official IEP meeting can be set up. In addition, the teachers should be notified that the parent will contact them to set up a meeting during the first week of classes to discuss the contents of the letter.

Initial meeting with the classroom teachers: Immediately after the letters have been sent to the teachers, the parent needs to make a follow-up phone call. The purpose of the call is twofold: first, to confirm that the teacher received the introductory letter, and second, to set up a brief meeting during the first week of classes. In Elizabeth's case, the first conversation with one of the teachers revealed that none of the teachers had received the introductory letter. The letters had been misplaced, and a quick phone call to the high school secretary rectified the situation.

As noted in the letter, a brief meeting needs to occur during the first week of class. Meeting times are set around each teacher's schedule. As mentioned before, the beginning of the school year is very busy and in all fairness to the teachers, parents should be sensitive to their schedules. Meetings need be no longer than 10 to 15 minutes. The meeting is to ensure that the teachers have read and understood the contents of the introductory letter; to inform them that an IEP meeting is forthcoming; and to initiate a communication log. The communication log can take the form of a daily progress report.

Daily Progress Report: The *Daily Progress Report* should be an adaptation of the standard progress form used in the school. A copy of the Daily Progress Report used with Elizabeth is found in Table 2. You may want to adapt the standard progress form that your school uses.

The categories in the first column are the same categories as those targeted for student evaluations. Ratings from 0 through 4, with 0 as "Unacceptable" to 4 as "Outstanding", were also a part of the school's progress forms. The student's progress is monitored daily rather than reported only at mid term and at the end of the reporting period.

The *Daily Progress Report* is a communication tool through which the student, student's parent and the teacher monitor progress. The student records assignments and due dates. At the end of the class, the student must make personal contact with the teacher. The teacher, in turn, checks the accuracy of the assignments recording and indicates the level of progress for the day's class behavior. If a special message needs to be conveyed, the teacher writes it at the bottom of the form. Parents review and discuss the *Daily Progress Report* with their child after each school day. Parents can also correspond with the teacher by writing short notes on the bottom of the page. An example of dialog with Elizabeth's algebra teacher is as follows:

> *8/26 Teacher: Elizabeth took a quiz in class -- from now on she'll take it after class and take a bit more time.*
>
> *Parent: 8/26: Do you think E needs any clarification for the quiz? She's studied and reviewed--If there is a problem with the next quiz, we might go to graph paper. Let's talk soon. Thanks*

This form keeps the parents, the teachers and the student informed about progress. Messages can be sent with a minimum of effort, and lines of communication can be kept open. After the *Daily Progress Report* has been in place, refinements for individual teachers can be introduced when necessary.

IEP meeting *Membership of IEP team:* At the secondary level all teachers, not just a representative from among the classroom teachers, who instruct the student should be invited to the initial IEP meeting. Parents can request that all their child's teachers be invited. Teachers and the content they deliver typically vary in instructional presentation and skill demands, e.g., algebra and English. While both classes share common requirements—like note taking or examinations—such requirements can differ in format and degree, as well as in the ease of providing accommodations by individual instructors. The type of accommodation that works in an algebra class may not generalize to an English, science, foreign language, drama, or shop class. The type of accommodation that the algebra teacher feels comfortable with may not be acceptable to another instructor.

If teachers have been trying out accommodations and the parents and teachers have been in daily contact, discussion at IEP meetings can focus on concrete rather than theoretical examples of appropriate instructional delivery.

Follow-up prior to meeting: Once a formal date has been established for the IEP meeting, a follow-up note by the parents is a wise safeguard. Communication with multiple parties is not always easily accomplished; backup systems facilitate communication. A phrase related to the date and time of the meeting casually jotted at the bottom of the *Daily Progress Report Form*, is helpful, but not intrusive. Phrases such as *looking forward to seeing you at Friday's IEP meeting* or *Glad to meet with you next week at the IEP meeting*, serve to ensure that the classroom

continued on page 68

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Table 2. Daily Progress Report

Elizabeth's Daily Progress Log

Subject: ____________________

3rd Quarter

Dates: ____________________

Elizabeth fills in the Assignment sections. Teachers check for accuracy.

	Monday	Tuesday	Wednesday	Thursday	Friday
Assignment Readings Due Date					
Assignment Worksheets & Labs Due Date					
Assignment Tests Date of Test					
Test Scores					
Homework					
Attention in Class					
Participation Cooperation					

4 = Outstanding, 3 = Very Good, 2 = Satisfactory, I= Needs Improvement, 0 = Unacceptable, NA = Not Assigned

Comments: ____________________

____

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Circle #16

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teacher is aware of the meeting time and date while not undermining the role of the special education personnel who set up the meeting.

Focused Meeting: IEP meetings that are focused are also likely to be brief, on target, and pleasant experiences. When numerous teachers are involved, IEP meetings need to be efficient. Meeting time is scarce and precious. Information taken from the *Daily Progress Report* can be used to streamline the meeting. These Reports can be used to discuss the type and extent of modification already in place in each inclusion classroom.

In Elizabeth's case, for example, the algebra teacher was concerned about her ability to complete tests in class. As a result, the algebra teacher reduced the number of items but kept the essential concepts on the test. The science teacher, in contrast, gave only short multiple choice tests which did not require any modifications for Elizabeth. The science teacher did, however, present a lot of information through notes not available in the class text. The solution to this potential problem was to give Elizabeth a duplicate set of class notes used by the teacher.

If teachers have been trying out accommodations and the parents and teachers have been in daily contact, discussion at IEP meetings can focus on concrete rather than theoretical examples of appropriate instructional delivery. At Elizabeth's IEP meeting, which took less than 30 minutes, discussion was task oriented; goals, objectives, and accommodations were officially decided.

After the IEP meeting: The IEP team shares responsibility for implementation of the IEP. The teachers deliver instruction, the student follows the direction of the teachers, and the parents assist the student and teachers to reach the goals of instruction. Parental assistance is effective only as long as communication is consistent and timely. In short, the *Daily Progress Report* continues to be used between parent, teachers and student. The detail and degree of communication varies according to the needs of the student. For some students a *Daily Progress Report* is fine, other students may advance to a *Weekly* and then *Monthly Progress Report*.

It is important for parents to act as the cornerstone of the IEP team in anticipating future problems, needs, or changes. The approach that I used for Elizabeth enhanced the teachers understanding of her school performance and communication with each other. I believe it can be a useful model for all high school students with special needs. The most positive service parents can provide is to keep communication regarding student progress clear with a well designed plan. ■

Kathleen M. McCoy, PhD, is an Associate Professor of Special Education at Arizona State University. In addition to teaching, she is doing research on techniques that promote inclusion of children at risk in general education settings.

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DO'S AND DON'TS FOR PARENTS AND TEACHERS

Some Pointers for Successful IEP Meetings

While Individualized Education Plan (IEP) meetings may always have some rough spots, they need not be like the gladiators facing off against the lions. Following are a few general ideas for parents and professionals to keep in mind when sitting down together.

Do's and Don'ts for Parents

- Do have realistic expectations about what the school can and cannot do
- Do become an educated parent
- Don't assume the school can do everything without your assistance
- Do be honest
- Don't immediately leap to the defensive
- Don't wait until a problem becomes serious
- Do take advantage of back-to-school night
- Do talk to other parents
- Do make sure you understand the terminology
- Do request regular communication with your child's school
- Don't dredge up the past
- Don't get angry
- Do adopt a positive attitude
- Do remember that you are the expert on your child

Do's and Don'ts for Teachers

- Do create an atmosphere of warmth and good feelings
- Don't sit behind your desk
- Do remember that if the parent perceives you as indifferent, the relationship will be strained
- Do be especially sensitive to body language
- Don't use language that is jargon-based
- Do write report cards, notes, and reports that are clear and concise
- Don't threaten, scold or set yourself up as the authority
- Do become acquainted with community resources
- Don't show disbelief regarding any information
- Do be honest with parents
- Do remember that the reality of any situation differs depending on the point of view
- Do make every effort to convey to the parent that his or her child is likeable
- Do let the parent know when something positive happens
- Don't be discouraged by parents who seem to make demands
- Do develop mutually agreed on goals
- Do remember that the parent is the expert on his or her child

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PARENT TIPS:

Getting the Most Out of IEP Meetings

Excerpted from Your Premature Baby and Child with permission from the authors.

by Amy E. Tracy and Dianne I. Maroney, RN

Berkley Books, New York, 1999, 334 pages

Your Premature Baby and Child is a parenting guide dealing exclusively with premature babies, their parents, and the professionals involved in their care. This is a comprehensive resource beginning with the child's homecoming and covering medical concerns, feeding, growth, school, and coping with emotional issues. There are five appendices at the end of the book that include information on handling medical emergencies, conversion tables, family resources, a glossary, and references. Throughout the book are quotes from parents of premature babies dealing with a wide range of parenting situations. Following is an excerpt from chapter 15, "Your Child with Special Needs," which deals with IEP meetings.

Some parents who have participated in the IEP process use words like "intimidating," "frustrating," and "confusing" to describe their experiences. Others find the IEP process "enlightening" and "helpful." Most likely you will feel a little anxious when you face the IEP team. Adding to that stress is the fact you are about to make major decisions regarding your child's future. By knowing what to expect and being prepared, you can make the most of your IEP meetings. Consider the suggestions given below from parents who have been there.

Before the meeting

- Come prepared with a notebook of information and records on your child. You can even send a copy in advance. Some things you might want to include in the notebook are your child's evaluations and assessments, school progress reports, medical records (including hospital discharge summary), therapy reports, correspondence with the school or medical professionals, homework samples, and your own report/assessment of your child.
- Meet with your child's teacher and therapists. Get a feel for your child's strengths, weaknesses, and current levels of accomplishments. You can do some of this by telephone.
- Write down your ideas about your child's accomplishments and weaknesses. Try to determine what your goals are before the meeting. Are there any holes that are not being addressed in your child's education? Do you have any unanswered questions?
- Observe your child and see what things he is trying to do. Make those skills foremost in the IEP goals. Also, watch for frustration-causing experiences. These may be areas with which your child needs help.
- Ask for evaluation and assessment results before the meeting so you can prepare. (This is your right as a parent.)
- If given a choice of where to have the meeting, hold it in a comfortable location.
- Before the meeting, think about what your child needs for success in school and goals you would like your child to work toward in the next year. Also, think about what your family's priorities are. For example, it may be more important to you that your child works more on his fine motor skills, such as handwriting, and less on his gross motor skills in physical education class.
- Call the special education supervisor or school principal before the meeting and ask to be introduced to the team members. Even a short phone call will ease the tension of the first meeting.
- Request a sample IEP form and become familiar with the information that it contains.

During the meeting

- Provide the team with insights about your child—what he is like at home, after school, and on vacations.
- Discuss your child's strengths as well as his needs. The tests your child took may not represent your child as a whole person.
- Make suggestions in any area of planning.
- If you do not understand something, ask for an explanation.
- Make sure the supports and services the team discusses for your child are based on his individual strengths and abilities, specific difficulties, and/or learning needs—not on his disability. If you do not feel that this is what the team is doing, speak up and redirect the conversation.
- Document what is said at the IEP meeting. Get agreements in writing, as required by law.
- Ask the team what you can do at home to support your child's IEP.
- Ask for intermittent "report cards" on your child's progress and a midyear meeting to review your child's IEP.
- Pay close attention to the goals set for your child's IEP and make sure they are not things he can already do or is near mastering. Also, make sure they are not unrealistic.
- If you become emotionally upset during the IEP meeting, know that most members of an IEP team will understand if you ask for a brief recess.
- You do not have to sign the IEP at the meeting. You may want to take a few days to review it, then sign or request changes.

After the meeting

- Closely monitor your child's progress and discuss any concerns with an appropriate member of the team.
- Keep the lines of communication open at all times.
- Communicate your child's feelings and concerns to the IEP team. ■

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SPECIAL OLYMPICS
Celebrating 30 years of Athletic Achievement

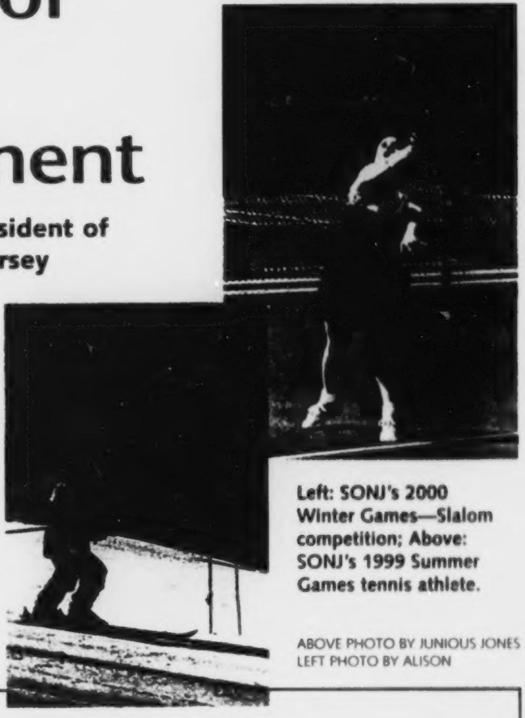
By Marc S. Edenzon, President of Special Olympics New Jersey

For all those people who have been involved with Special Olympics New Jersey (SONJ), this new millennium is a very big deal. More than just the dawn of the new century, 2000 marks the 30th anniversary of our state chapter. Celebrating the 30th Anniversary is particularly significant when one considers the abundant changes that have taken place in the lives of individuals with developmental disabilities. Now more than ever, understanding and acceptance have replaced confusion and negative preexisting ideas. Athletes who have years of competition experience under their belts are providing guidance and setting standards for many future athletes.

In 1970, the first SONJ state games were held at the Johnstone Training and Research Center. Despite heavy rain, more than 200 athletes, eager for the opportunity to demonstrate their courage and skill, participated. The movement in New Jersey had begun, and it continues to grow at a phenomenal rate. As we enter the new millennium, SONJ boasts more than 13,000 athletes and 12,000 active volunteers.

SONJ athlete Paul Butera has been involved with the program long enough to realize that definite advances have been made. According to Paul, however, one thing remains the same: "Special Olympics has always been about friends, athletes, coaches, parents, and volunteers coming together to have a good time."

Looking back over the past three decades, it is important to note some defining moments and people that have contributed to the rich history of SONJ as well as the success of the athletes. ■



Left: SONJ's 2000 Winter Games—Slalom competition; Above: SONJ's 1999 Summer Games tennis athlete.

ABOVE PHOTO BY JUNIOUS JONES
LEFT PHOTO BY ALISON

1969-70
Walter Johnson and Bessie Perlman are appointed Co-State Directors; Johnstone Training Center hosts first state meet; NJ attends International Games in Chicago; swimming is introduced as an official sport.

1970-71
The New Jersey Department of Community Affairs and Education endorses the Special Olympics; three area programs are certified.

1972
Alex Webster, Head Football Coach of the New York Giants, attends the Summer Games; Olympic Champion Carl Lewis meets and hosts the Burlington County athletes on Carl Lewis Day.

1975-76
First overnight State Games hosted by Rutgers University; state tournaments sponsored in swimming, basketball, bowling and ice skating; Franco Harris, former Pittsburgh Stealer running back, attends the New Jersey Special Olympics (NJSO) Summer Games.

1977-78
First New Jersey Winter Games held at Great Gorge; The National Soccer Skills Tournament is hosted by New Jersey at Fairleigh Dickinson University; nine area programs are certified.

1981-82
Winter and Summer Games expand to three days and New Brunswick becomes the new headquarters.

1983-84
Port Authority Police sponsor First Annual Torch Run from Statue of Liberty State Park to Summer Games at Rutgers; PIA joins NJSO; NJSO soccer athletes participate in full-day clinic with Pele and the New York Cosmos at Giants Stadium.

1984-85
Number of areas expands to 12.

1987-88
Seasonal Competition format is introduced.

1989
New Jersey figure skating athlete Cindy Reed is featured on "A Very Special Christmas," performing with Scott Hamilton in a pairs skating exhibition.

1990-91
New Jersey sends fifth largest team to International Summer Games in Minneapolis/St. Paul; Bob Reasso, Head Coach for Rutgers University, coaches NJ Team; New Jersey athletes Kristen Clark and Paul Butera compete in gymnastics at the United States Olympic Festival in Texas; Athlete Donald Pyscaty meets President George Bush and Arnold Schwarzenegger on the White House lawn during the Great American Workout.

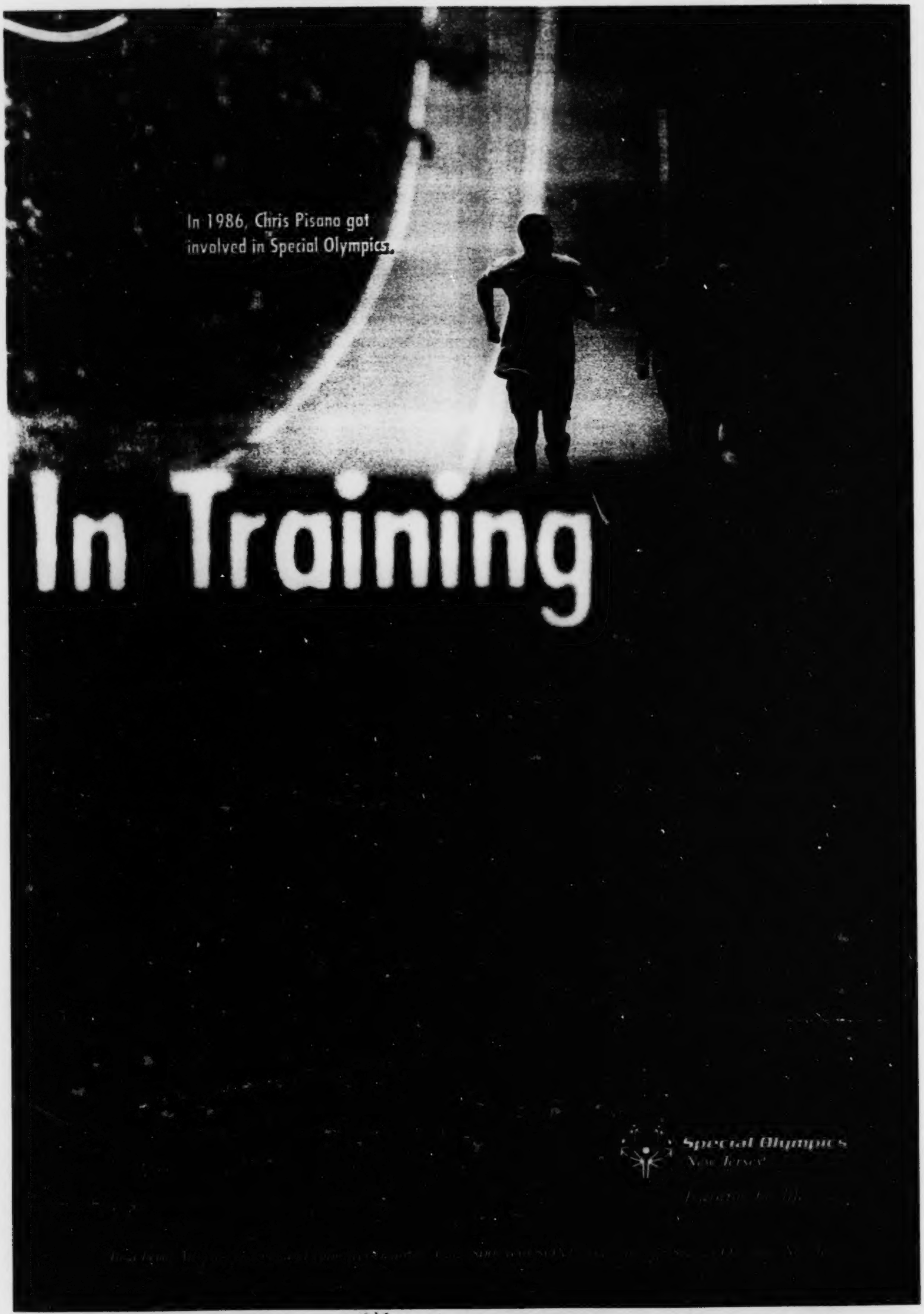
1991-92
League program expands to all team sports; NJSO athletes are featured on Good Morning America with Joan Lunden.

1993-1994
NJSO coordinates the 25th Anniversary Celebration for Special Olympics Incorporated at the United Nations in New York; Cindy Read meets President Clinton at the White House as a member of 1993 Team USA—New Jersey's delegation in the World Winter Games in Austria.

1995-96
Largest Winter and Summer Games in NJSO history are conducted; 3,200 new athletes sign on to school and summer programs; NJ Law Enforcement Torch Run ranks 3rd in the world; NJSO relocates to Princeton; Team USA-New Jersey Tennis athlete plays an exhibition match with Monica Seles; The Today Show, with Katie Couric and Bryant Gumbel, hosts athletes and coaches from Team USA—New Jersey.

1998
New Jersey Special Olympics changes name to Special Olympics New Jersey (SONJ); SONJ athlete Yamaira Santiago appears on a Proctor & Gamble Cover Girl ad with Nikki Taylor.

1998-99
SONJ athlete Nancy Filimonczuk is featured on a limited edition Wheaties box and in a "Got Milk?" campaign ad, published in the USA Today during the 1999 World Summer Games.



In 1986, Chris Pisano got involved in Special Olympics.

In Training

Special Olympics
New Jersey

[illegible]

Circle #69

TEE TIME FOR ALL

by David Chamalian

Golf is a game that can be enjoyed by everyone. Now more than ever, people who have physical disabilities are not only discovering that they are able to play good golf, but they are finding that the ominous wall of inaccessibility that once surrounded the game is now crumbling. Special programs and organizations nationwide are offering people of all ages with physical disabilities beginner lessons, and even the chance to get onto the course for a few holes or an entire round.

Adaptive equipment is making it easier for people who use wheelchairs to traverse golf courses safely or hit a ball from a wheelchair. Parents of children with disabilities are finding that golf makes ideal recreation for their kids, and the kids themselves enthusiastically welcome the chance to be outdoors and share the fun of the game with their peers. Even efforts to educate and convince golf-course owners and superintendents that making their courses more inviting and accessible to people with disabilities have also succeeded.

Golf programs nationwide are helping make golf more accessible to people with physical disabilities. This young golfer works on perfecting her swing and does not let her amputation impede her enjoyment of the game.

Tools of the trade

Scores of adaptive equipment and services are available for the golfer with physical limitations. For example, single-rider carts allow a golfer to play an entire round of golf without having to stand up. These carts are fitted with a swivel seat (manual, in most cases), allowing the user to swing from a seated position, and they provide access to golf-course terrain once considered inaccessible to people with physical limitations. Specially angled clubs are also available for seated golfers. Says Joe Arcese, a golfer who has T-4 paraplegia (paralysis from the chest down), "The manufacturer [of the angled clubs] will ask you how tall you are, how long your arms are, and how high your seat is, then custom-make the club for you." (He also says that any local metal worker can make the modifications for you.)

Flexible-shaft golf clubs are designed to give people with physical disabilities better distance on their strokes with less effort. For people with hand amputations, there are devices that attach to the prosthesis, slide onto the golf club grip, and grab tightly, allowing the user to swing with both arms. Many types of special grips are also available—many using Velcro® straps—giving the user a better grip on the club.

Other products include ball-teeing and ball-retrieving devices for people who have difficulty bending over, rubber tees (small mats with a protruding rubber tee), which can be attached to a single-rider cart by a cord and reeled in after teeing off, golf ball feeders that dispense balls directly to the awaiting player for more convenient, time-saving practice, and many more. (See Resources section.)

People with visual impairments can be paired with sighted guides, or coaches, who help by providing the essential information about each shot and guiding and aligning his or her partner's body in relation to the ball and cup. Says Tom Mirus, who is the director of rules and education at the US Blind Golf Association (USBGA) and who is legally blind, "A coach acts like a television commentator, describing what the situation is and helping the golfer with a visual impairment select a club for the shot." Mr. Mirus invites anyone who has a visual impairment and needs a guide, or anyone wishing to volunteer as a guide, to contact the USBGA.

Beyond the clubhouse and onto the course

One of the biggest questions in making golf more accessible to people with disabilities is: Should existing courses be remodeled to accommodate people with physical impairments, or should technology be responsible for bridging that gap?

Gary Robb is the executive director of the National Center on Accessibility, an organization that advocates for people with disabilities to be included in recreation, parks, and tourism. Mr. Robb believes there is a happy medium between accessibility on courses and keeping the game challenging: "I do not support changing the nature of the game...or that courses should become sterile and 'pancake' in nature. I do believe that technology devices can make courses more playable rather than being concerned about the physical structure of the course." Mr. Robb added that golf course owners can make some changes, however. "Course-friendly improvements would be welcomed. Most courses can become accessible by eliminating ropes, path barriers, and other obstacles that make it difficult for people with disabilities to play."

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Efforts to make golf accessible are on the course for success

One solution to accessibility, according to Arcese, who has played golf all over the country, is the single-rider golf cart for people who use wheelchairs. He admitted, however, that this type of golf cart is often unavailable, and "someone who plays a course in a wheelchair is going to have a difficult time of it." (Obstacles that wheelchair users face are: the inability to swing the club due to the arm rests; getting on the greens to putt where, in most cases, because of their narrow tires, wheelchairs are prohibited; managing the hilly terrain; getting in and out of sand traps; and preventing the chair from slipping and sliding on wet grass.)

Making the single-rider carts available at public courses has been the focus of Arcese's work in advocating for people who use wheelchairs and want to play golf. "There are quite a number of companies that make them. The problem is, very few people know they exist." (EP called twenty national public golf courses for this article, and none had single-rider carts available for rent). Nevertheless, he advised the following to people who want these carts made available at their local public course: Contact your county Parks and Recreation Department and make a presentation to the Board explaining that single-rider carts can also be used by ablebodied golfers, and that any public course, supported by public dollars, should be accessible to everyone. Arcese says the process is easy, and in his case, "I only asked that they buy one single-rider cart, but actually, they bought three: one for each of the public courses in the county. After I made the presentation, the first question they asked me was, 'Why don't we already have these?' "

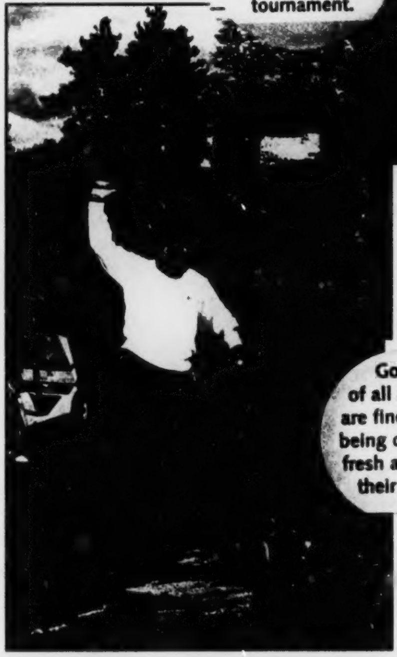
Enjoying the game is par for the course

Many organizations and programs are forming around the country to help make the game of golf more accessible to people with all types of physical limitations. One such program is Golf 4 Fun, a 12-year-old nonprofit golf-education program in Colorado and a chapter of Disabled Sports USA, a national organization that helps provide local services for people with disabilities who wish to participate in sports and recreation activities. Golf 4 Fun hopes to be a model for other golf-program organizers to follow in using the game as a means of physical and recreational therapy.

Golf 4 Fun provides group and individualized instruction on the basics of the game of golf. PGA professionals are hired to teach people of all ages how to play golf as beginners or how to return to playing after a disability. The program also relies on the services of volunteer therapists i.e., physical, recreational, and volunteers from local recreation departments to be present during the classes to work with each student as their needs warrant. According to Golf 4 Fun's Chairman Bob Nelson, the program "is simply a golfers-helping-golfers rehab program for individuals with physical disabilities. It doesn't teach people [with physical disabilities] to be great golfers."

According to Mr. Nelson, programs similar to his can be started in any community. "First, you need to go to your city or county Recreation Department and make a proposal. They are usually cooperative and are always looking for new programs to offer. Get the use of a driving range—most likely a public facility. Then you need to hire qualified, professional golfers to teach. Do your fundraising, and most important, advertise in the paper or through your town for used golf equipment. Everybody's got used golf equipment, and once people find out about your program, you'll soon have more donated equipment than you know what to do with."

This 13-year-old boy with dystonia admires his tee shot during a golf tournament.



Golfers of all abilities are finding that being out in the fresh air boosts their spirits.

Golfers of all ages get into the swing of golf

Retired physical therapist Isadore Brown, who has worked with both skiers and golfers with disabilities, is an advocate for golf as therapy. Known as "Brownie" to all who know her, she is currently a volunteer therapist with Golf 4 Fun, where the philosophy of "mainstreaming" participants in the program

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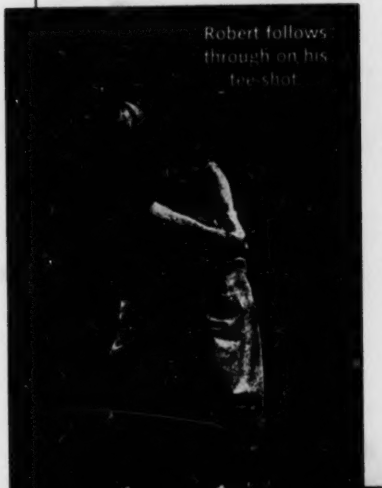
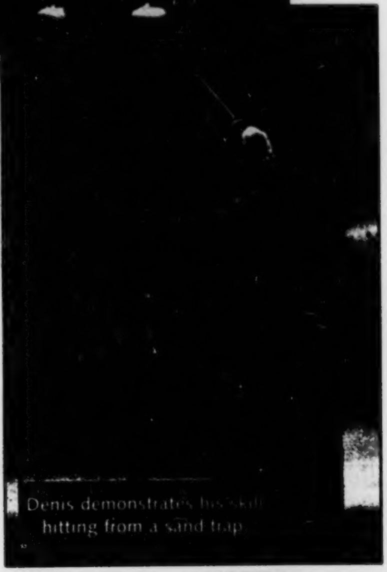
Medalists Hit the Big Time



Robert follows through on his tee shot.



Denis demonstrates his skill hitting from a sand trap.

PHOTOS COURTESY OF JOSEPH EPSTEIN

EP's June cover features two members of the Special Olympics New Jersey golf team who were recently chosen to appear on the Team Cheerios cereal box. Robert Elfreth and Denis G.T. Hagios, who both have Down syndrome, were awarded this honor in recognition of their passion, dedication, and achievements in the sport of golf.

Robert, of Haddon Heights, NJ, who is known for his putting and chipping skills, began playing golf in 1992. Within three years, he was representing New Jersey at the Special Olympics at their World Games, where he won a silver medal. In 1999 he and his then teammate, Doug Endee, won the gold medal at the same games in the Unified Golf competition. One of Robert's goals is to one day birdie a hole. "Special Olympics changed my life," beams Robert. "I'm independent, confident and a team player!"

For Denis, of Flemington, NJ, whose parents are avid golfers, golf is in the blood. He puts his nose to the grindstone when it comes to studying the game. In 1995 Denis garnered a bronze medal with his foursome partners in the Special Olympics World Games in the Alternate-Shot competition. Four years later at the same games, Denis won a gold in the nine-hole Individual-Stroke competition.

According to Doug Endee, who is a physical education teacher at a special education school in Camden, NJ, and has played frequently with both Robert and Denis, the awardees are exceptional young adults. "I've been a coach for twenty years, and I've never had a better experience than playing with these tremendous athletes. They really embody the pure fun of the sport, and their disability is really just an afterthought." (Though both Robert and Denis can play eighteen-hole courses, Special Olympics competitions are only nine holes.)

To be eligible for the golf program of Special Olympics of New Jersey, participants must be age 8 or above with mental retardation or other closely related developmental disabilities. For more information on Special Olympics of New Jersey, call (800) 650-7665, or log onto their Web site: http://www.sonj.org. For the Special Olympics program in your state, call the Special Olympics headquarters in Washington, D.C. at (202) 628-3630; Web site: http://www.special olympics.org.

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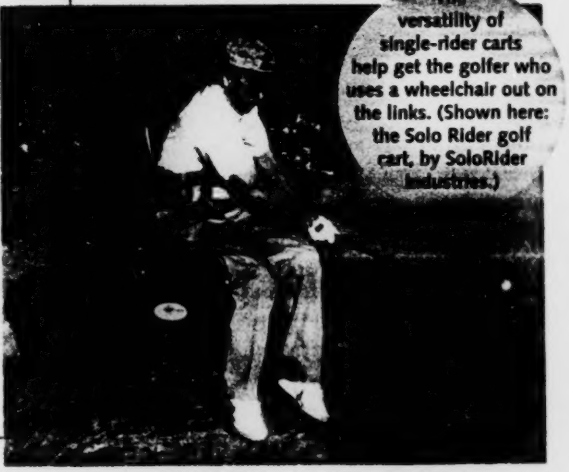
is manifested by helping them get involved in their communities through golf. "The instructors and therapists are encouraged to look beyond the walls of a hospital or clinic when instructing. Self esteem is a big goal [for the students]."

Having a therapy professional in the golf-learning environment is an advantage, according to Brownie. "As therapists, we can see ways to make golf more practical and have a little better understanding of the way one might improve his [or her] swing." However, she admitted, working with people with disabilities does not always require being a pro. The beauty of golf is that modifications to a person's game can be individualized; for example, someone who is right-handed—but has limited use of that side—can learn to play from the left side. Setting up more than one ball, or target, on the hitting surface can help someone with blurred or poor vision make a shot.

Golfer Mark Frace works for the United States Golf Association (USGA) Foundation Fellowship in Leadership and Service program, assessing and analyzing grant applications for nonprofit golf programs that introduce new players of all abilities to the game. "Golf gives people a chance to get out and meet other people," explains Mr. Frace. "This effort is part of the USGA's 'For the Good of the Game' commitment, over the next ten years, to make golf affordable and accessible. Golf brightens up people's spirits and confidence, and we try to promote these programs as much as possible." Since 1997, the USGA has awarded $500,000 in grants for golf programs for individuals with disabilities.

Through the USGA Foundation, Mr. Frace is



The versatility of single-rider carts help get the golfer who uses a wheelchair out on the links. (Shown here: the Solo Rider golf cart, by SoloRider Industries.)

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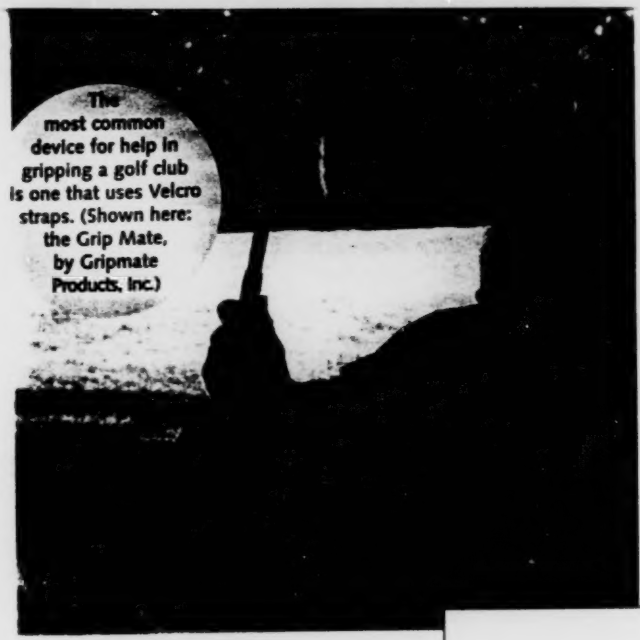
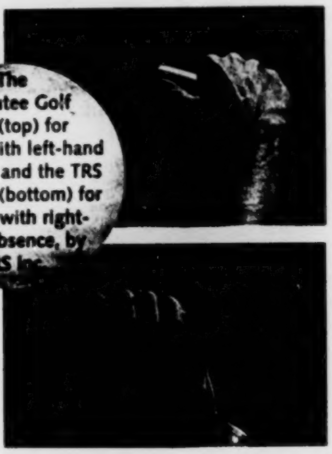


The most common device for help in gripping a golf club is one that uses Velcro straps. (Shown here: the Grip Mate, by Gripmate Products, Inc.)

also establishing a Golf Resource Center for Individuals with Disabilities, a national clearinghouse of information designed to provide as many resources as possible to all individuals with disabilities wishing to play and enjoy golf. "

Mr. Frace, who has had no use of his left arm since birth due to left-hemi dystonia, began playing golf as a child as an activity his whole family could do together. Today he is an accomplished, competitive golfer, and can relate through his own personal experience the importance of making golf accessible to everyone. "I can enjoy golf with the whole family. Golf is a game that everybody can play together."

Another attractive feature of golf is that it can be as equally enjoyable and beneficial for youngsters as it can be for adults. Bob Buck, the president and founder of the Eastern Amputee Golf Association (EAGA), an organization that conducts golf tournaments, seminars, outings, and clinics for all physically challenged people throughout the eastern US, has only praise and encouragement for the kids who choose golf as recreation. "In most cases, children with disabilities are much more adaptable than their parents. They are exceptional in trying sports and being active outdoors." (EAGA membership is open to any individual who has experienced the loss of one or more extremities at a major joint due to amputation or birth defect. Free instructional videos are available to its members.) According to Mr. Buck, an important aspect of golf for children is sharing the experience with other kids with disabilities. "The main thing is that you can get outdoors.....and getting a chance to smell the flowers is important." ■



The Amputee Golf Grip (top) for golfers with left-hand absence, and the TRS Golf Pro (bottom) for golfers with right-hand absence, by TRS Inc.

Resources

Organizations:

Amputee Coalition of America
900 East Hill Ave., Ste. 285
Knoxville, TN 37915-2568
Phone: (888) 267-5669
Web site: http://www.amputee-coalition.org

Disabled Sports USA
451 Hungerford Dr., Ste. 100
Rockville, MD 20850
Phone: (301) 217-0960
Web site: http://www.dsusa.org

Eastern Amputee Golf Association
2015 Amherst Dr.
Bethlehem, Pennsylvania
18015-5606
Phone: (888) 868-0992
Fax: (610) 867-9295
Web site: http://www.eaga.org

Golf Resource Center for Individuals with Disabilities
Phone: (719) 471-4810 x18
Web site: http://www.usga.org

National Amputee Golf Association
PO Box 23285
Milwaukee, WI 53223-0285
Phone: (800) 633-NAGA (6242)
Web site:http://www.amputee-golf.org

National Center on Accessibility
Indiana University
5020 State Rd. 67 N.
Martinsville, IN 46151
(765) 349-9240
Web site:
http://www.indiana.edu/~nca/

US Blind Golf Association
3094 Shamrock St. North
Tallahassee, FL 32308-2735
Phone: (850) 893-4511
Web site:
http://www.blindgolf.com/United_States/u_s_home_page.htm

US Golf Association Foundation
1631 Mesa Ave. Copper Bldg.
Colorado Springs, CO 80906
Phone: (719) 471-4810
Web site: http://www.usga.org

For information on adaptive golf equipment, contact:

Eastern Amputee Golf Association
(see above)

Abledata
8401 Colesville Rd., Ste. 200
Silver Springs, MD 20910
(800) 227-0216

Golf programs:

Golf 4 Fun
PO Box 5304
Englewood, CO 80155
Phone: (719) 520-4694
Web site:
http://www.golf4fun.org

Products:

Gripmate Products, Inc.
Phone: (800) 941-4505

Solorider Industries
Phone: (800) 898-3353

TRS Inc.
Phone: (800) 279-1865

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Strength and Conditioning Exercises

The Special Olympics Motor Activities Training Program works on strength, conditioning, and motor awareness.

For the body to function optimally, whether in sports or in daily living, strength is a necessity. Fortunately, it is very easy to improve strength and conditioning. Following are some simple movements using resistance (for example, exercise bands, gravity, and body weight) which can improve strength and ease of movement. (Note: No exercise program should be started without physician approval.) These exercises can be performed in a seated position, independently, or, if necessary, with assistance.

Performing strength exercises using exercise bands

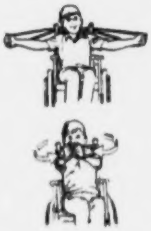
Exercise bands are stretch bands that, when used properly, can provide a comprehensive isokinetic strengthening program for all participants regardless of their disabilities. Exercise bands that can be commercially purchased include Thera-Band® (Hygenic Corp.) or Resistive Exercise Products (REP) Bands by Magister Corp. (See Resources box). Both resistance bands come in a variety of lengths and resistance levels. Thera-Band has latex and latex-free versions. Resistive Exercise Products Bands are latex-free. Exercise bands can also be made by using cut-up strips from inner tubes. The following are selected activities that can be used with exercise bands.

Thera-Band® exercise band.

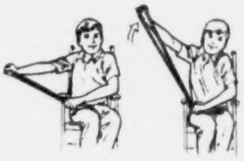
Note: Exercising with exercise bands can be dangerous. Always make sure the bands are in good condition before using them. Never allow anyone to use the bands without proper supervision. Never use the bands in such a way that may cause it to snap towards the head. Always consult the participant's therapist to find out if exercise bands are appropriate.

Chest and shoulders:

Hold exercise band at both ends and bring over head and around back of chair. Regrip bands as necessary so that arms can be extended as fully as possible to the side and so that the band is pulled taut. Without bending elbows, slowly bring hands together in front of chest. Hold position for one second then slowly bring arms back to starting position. Repeat 8 to 12 times (if tension is too much for a participant, allow band to have more slack when starting, have participant pull one arm at a time, or provide assistance).



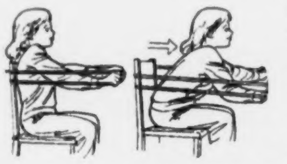
Shoulders: 1) Hold exercise band at both ends and in front of body so that arms are approximately shoulder width apart and extended out. Make sure band is taut. Slowly pull hands away from each other trying to maintain straight arms. Hold maximum pull for one second then slowly bring hands back to starting position. Repeat 9 to 12 times with assistance as necessary.



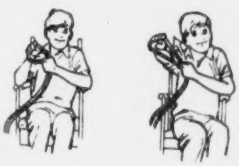
2) Hold exercise band to side of wheelchair so that lower hand is holding exercise band to chair and upper hand is parallel to floor and extended outward. Regrip band as necessary to increase or decrease tension. Slowly lift upper hand away from lower hand while maintaining position of lower hand. Hold maximum pull for one second then slowly bring upper hand back down to starting position. Repeat 8 to 12 times, then do the same with the other arm. Provide assistance as needed.

Stomach:

Hold exercise band at end and wrap it around back of wheelchair. Regrip band as necessary so that arms are bent and held into body and maximum tension is achieved. Without moving arms or hands, slowly bend forward. Hold maximum pull for one second, then slowly lean back to starting position. Repeat 8 to 12 times providing assistance as necessary.



Back of arms: Hold exercise band with both hands. With elbows on arm rests, have one hand against chest and the other hand slightly beyond chest with palm facing out. Regrip band as necessary to get maximum tension. While keeping hand on chest, slowly push the other hand out and down toward arm rest. Hold one second at maximum pull then slowly bring hand back up to starting position. Repeat 8 to 12 times, then do the same with the opposite arm with assistance as necessary. ■



Adapted from "Motor Activities Training Program Guide."

For more information, contact:
Special Olympics International
1325 G St., NW, Ste. 500
Washington, DC 20005
(202) 628-3630 • (202) 824-0200 (fax)
Web site: http://www.specialolympics.org

RESOURCES
Thera-Band®
The Hygenic Corp.
(800) 321-2135
Web site: http://www.thera-band.com

REP Bands
Magister Corp.
Available through:
- Smith + Nephew: (800) 558-8633
- or online at eWellness.com

Website: http://www.ewellness.com

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Adventures for the Senses

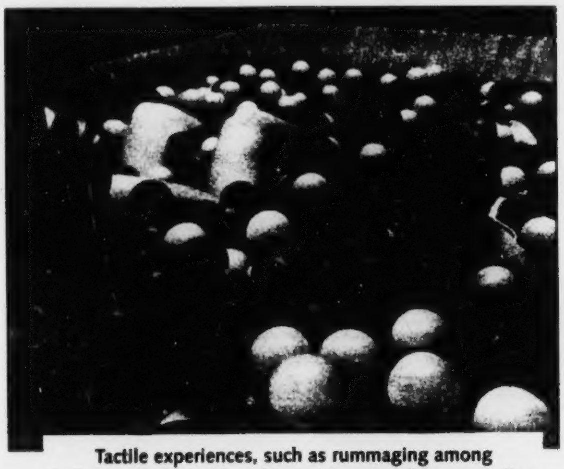
Fun is all around at Sensory Adventure Camp

by Ingrid M. Provident, MS, OTR/L

PHOTOS BY SANDRA L. MARLIN

During a meeting with some parents at a community play center, I was asked if Duquesne University (where I work) would be willing to support a parent-initiated effort to create a sensory experience camp for special children. One parent had been taking her daughter to a local gymnastics group and was upset at the difference between her child's motor performance and that of the other children. Out of this frustration grew a fun and innovative motor and sensory experience for children with developmental delays: Sensory Adventure Camp.

Sensory Adventure Camp is based upon Sensory Integration Theory and the work of Jean Ayres; however, it is not therapy. It is simply an opportunity for parents and children to experience play geared toward sensory stimulation. The activities at Sensory Adventure Camp are grounded on the idea that the central nervous system develops and is enhanced by sorting out and connecting input from the environment through the body's sensory systems.



Tactile experiences, such as rummaging among ball-pit balls for hidden objects (above) and fingerpainting (below), are among the many fun, yet purposeful activities offered at Sensory Adventure Camp.

Children with sensory processing disorders cannot sort out the sensory information; therefore, they exhibit atypical behaviors in reaction to the input they receive through their senses. They may have extreme reactions to the task of toothbrushing, for example, and may cry, resist, or dislike the sensations of the activity because they cannot integrate them.

Children naturally seem to seek out the experiences that they can process. Drawing on that natural inclination, we allowed each child at Sensory Camp to select the activities in which he or she wanted to participate. Each session has a theme with corresponding activities. Camp participants are encouraged to explore eight challenging stations that are focused on different sensory activities. Typically, sensory experiences include tactile (touch), vestibular (balance), olfactory (smell), and gustatory (taste) as well as gross/fine motor (large and small muscle actions).

Getting started

To help the concept become a reality, a committee was formed including parents, an occupational therapist, a physical therapist, and an early development specialist. These committed volunteers developed a plan of action:

- The Camp would be held for three hours, one day per week, in six-week sessions.
- Different themes were developed for each of the six consecutive weeks.
- Volunteer occupational therapy students were recruited to run the activities. Volunteer professionals provided supervision for the children's safety, and monitoring of physiological and behavioral responses.
- The Camp needed a place "to be." The group found that the Center for Creative Play, the community's inclusive play center, had a conference room available for use on Sunday mornings.
- Equipment needed was provided by the University and transported there for the day.

Though it is still in its formative stages, Sensory Camp now has a two-year track record of providing motor and sensory experiences for special-needs children. Children with autism, cerebral palsy, and many others have

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enjoyed the activities designed at the Camp. The OT students, participating as Camp staff, have an opportunity for hands-on learning.

Some "sensory adventures"

Here are examples of activities based on a circus theme. (All Campers and activities were carefully supervised and supported by the Camp staff.)

Tactile: We filled a child-size swimming pool with ball-pit balls. Children were encouraged to get into the middle of the ball pit and find circus props, such as little plastic clowns, buried within the balls.

Vestibular: Seated on a T-swing, children assembled an image of a clown by placing pieces of felt on a board in front of the swing. The children leaned down to pick up felt pieces from the floor and placed them on a felt-covered board on the wall. While any swing will work, the T-swing, which resembles an upside-down T, allows the child to hold onto the center support. The movement of the swing provides stimulation to inner ear receptors, which will help the child with balance and organizing his or her movement through space.

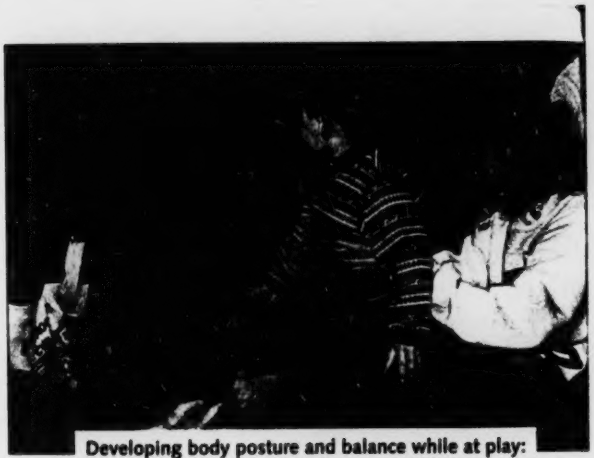
Taste/smell: Popcorn was popped and offered to taste.

Gross motor: Children were encouraged to walk on a floor balance beam while holding a balance stick, pretending to be a tightrope walker. Another activity was to allow the child to step through hoops placed on the ground while wearing large clown shoes.

Fine motor: The children were encouraged to make a sock clown, designing its facial features and dressing it, which they could take home afterward. Children also had the opportunity to experiment with painting their own faces to look like a clown.

Another theme was "Seasons" and the related activities were:

Tactile: The children were encouraged to feel grass carpeting while walking barefoot and to jump into a pool filled with Easter-basket grass.



Developing body posture and balance while at play: This activity involves helping a child balance on a ball, while an OT student draws the child's focus to the puppet.

Marbridge

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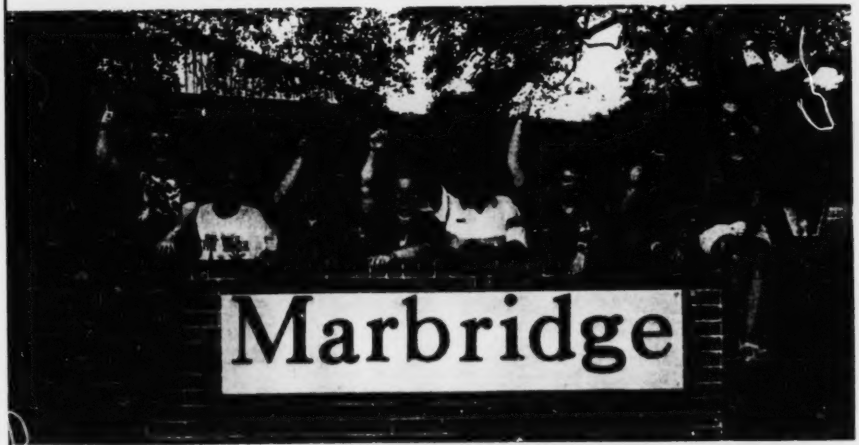

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Vestibular: Using a swing again, the children were asked to separate items placed under the swing into the four season categories. Items included mittens, swimsuits, leaves, etc.

Taste/smell: Flowers were available to smell; ice cream was available to taste.

Gross motor: The children were asked to dress up in different seasonal clothing and ride a scooter board to the next station, where they would have to undress and put on another season's clothing.

Fine motor: The children made a rain stick by putting rice into a tube and then sealing it closed. They were able to take their creations home to remember all the fun they had had in camp.

An individual experience

Based on the child's response to the activity, the student volunteer can alter the activity slightly to make it more meaningful to the child. For example, if a child does not like to be touched by something cold, the volunteer may start with objects less extreme in temperature and gradually build to an experience of tolerating the cold.

The occupational and physical therapy as well as education students are able to engage in constructive activity with children to whom they may not otherwise have been exposed. This invaluable experience could never be taught in a classroom. By making it multidisciplinary, students also learn to interact with other professionals.

The parents seem to find it an excellent opportunity for their children to explore and a forum in which to ask questions of professionals in a non-threatening environment. According to one camper's parent, "It exceeded my expectations. It allowed the kids to explore their senses and find what they liked." Parents have also found that it provides opportunities to network with peers and professionals.

Sensory Camp is a learning environment for all: Parents, kids, health profession students and staff. I would encourage any parent experiencing frustration to turn their energies into an exciting opportunity. Call a local health science school or university in your area and ask for support in starting a Sensory Camp. It is a win-win situation for all involved. The Camp gives the University a prime training ground for students and an opportunity to work with people in the community. Most important, the children can have fun while making some sense of the sometimes intimidating world around them. ■

Ingrid M. Provident, MS, OTR/L, is an Occupational Therapy Instructor at Duquesne University, Pittsburgh, PA. Anyone interested in contacting Ms. Provident for more information may reach her at:

Duquesne University
227 Health Science Building
Pittsburgh, PA 15282
Telephone: (412) 396-5411
provident@duq.edu

SUMMER CAMPS & PROGRAMS FOR CHILDREN WITH SPECIAL NEEDS

Children's Specialized Hospital offers a variety of summer camps and programs for children and adolescents with physical, developmental, and learning disabilities.

CSH-MOUNTAINSIDE

CAMPOREE:
Crafts, music, theme weeks, cooperative games and social skills for children who have physical disabilities, PDD or autism. Participants must be able to work in small groups. Siblings within the same age groups may also register.

UNDER THE UMBRELLA:
Crafts, music, theme weeks, cooperative games and social skills for children who have physical disabilities, PDD or autism. Participants must be able to work in small groups. Siblings within the same age groups may also register.

COMMUNIKIDS I & II:
A speech therapy and recreation program for children with mild to moderate speech disorders. The program will carry over oral motor, communication and socialization skills during the summer. Program goals will be derived from the child's IEP. A current speech evaluation (within the last 6 months) is required. Some insurance companies may cover the cost of this camp as a therapeutic program. You must check with your insurance carrier to verify coverage.

RAINBOW FISH:
Beginner instructional swim program for children with physical disabilities and/or developmental disabilities, PDD/Autism and ADD/ADHD. Parent participation in the pool will be encouraged.

MARTIAL ARTS:
Martial arts instruction for children with ADD/ADHD, cerebral palsy, or any diagnosis causing gross motor or fine motor problems. The program will help develop body awareness, balance skills, coordination, and attention skills.

PROGRAM FOR TEENS

TEEN TRAVEL PROGRAM:
A variety of day and overnight excursions to locations such as Philadelphia, Lancaster, PA, Baltimore Inner Harbor and New York City are planned for teens 13-18 years of age with a variety of special needs. Trips will depart from and return to Children Specialized Hospital - Mountainside

CSH - OCEAN

ADAPTED HORSEBACK RIDING:
A basic instructional horseback riding program for children and adolescents with physical disabilities or movement dysfunction. Participants must be able to follow simple directions.

CHAT AND SNACK:
An instructional group program designed to strengthen and improve movements for talking and eating.

DEVELOPMENTAL DANCE:
A dance program for children with cerebral palsy, developmental delay, hypotonia, Down Syndrome, physical disabilities or any diagnosis causing gross motor, fine motor, or social interaction delays. The program helps develop body awareness, balance skills, coordination and social skills.

KUNG FU/KARATE:
Martial arts instruction for children with ADD/ADHD, cerebral palsy, or any diagnosis causing gross motor or fine motor problems. The program will help develop body awareness, balance skills, coordination, and attention skills.

MOVERS AND SHAKERS:
An instructional program with a focus on sensory motor, fine and gross motor skill development.

PALS PARADISE:
Creative arts, drama, martial arts, and crafts for children with physical or developmental disabilities. A sibling or friend within the same age group are welcome to register.

READY, SET, SCHOOL:
A program to enhance pre-writing skills for children with fine motor difficulties.

Children's Specialized Hospital
An Affiliate Member of the Robert Wood Johnson Health System

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Exceptional Parent

June 2000

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MEDICAL RESEARCH UPDATE

BY DAVID CHAMALIAN

DOWN SYNDROME CHROMOSOME DECODED

A team of scientists has successfully sequenced the DNA of chromosome 21, which is the most common genetic link to Down syndrome. (People born with Down syndrome usually carry three copies of chromosome 21, instead of the usual two.) The foremost benefit of identifying these genes and understanding how, when, and where they operate could bring scientists closer to developing gene therapy to treat the syndrome. Dr. Roger H. Reeves, a geneticist at Johns Hopkins University says, ".....Defining the players and the playing field is a very major step that the Down syndrome community has been working toward for years." The research team makes up part of the consortium of academic centers led by the National Institutes of Health and the Wellcome Trust of London. The research was published in the May 18, 2000 issue of *Nature*.

AUTISM AND VACCINES: NO LINK, SAY DOCTORS AND RESEARCHERS

Two prominent health organizations, the American Academy of Pediatrics (AAP) and the National Network for Immunization Information (NNII), testified before a U.S. House Government Reform Committee that no scientific evidence exists linking autism to any of the vaccines commonly administered to young children. The Committee was convened to look into the marked rise in autism diagnoses in the US, and claims that childhood vaccinations may be the cause. The two organizations (among others, including the Center for Disease Control and Prevention [CDC]) stand by their recommendations that the measles-mumps-rubella (MMR) vaccinations—those most widely blamed for the apparent increase in autism—continue as normal. Vaccines remain the safest way, the organizations say, to protect children against potentially devastating infectious diseases. The President of the AAP, Donald Cook, MD, says, "While I support any effort to discover the reason a child has autism, current scientific data indicate that vaccines are not the cause. What a tragedy it would be for any child to suffer the consequences of a disease that could have been prevented by vaccination." Critics of routine vaccinations claim that because the signs of the disorder begin to show during the first three years of life—a time when most vaccinations are given—there must be a link. Meanwhile, the AAP and other health researchers continue to look into other possible causes of the disorder. For more information, call the CDC at (800) 311-3435, or go to the following CDC URL address: http://www.cdc.gov/nip/vacsafe/ concerns/autism/.

NEW ADHD DIAGNOSIS GUIDELINES ISSUED

The American Academy of Pediatrics (AAP) issued this month stronger guidelines in evaluating and diagnosing children with attention-deficit/hyperactivity disorder. The new recommendations can be summarized as follows: 1) The explicit clinical criteria set out in the "Diagnostic and Statistical Manual of Mental Disorders" must serve as the basis for making ADHD diagnoses; 2) Children must be evaluated for disorders that coexist and are associated with ADHD—such as conduct disorder, oppositional defiant disorder, mood disorders, depression, anxiety, and learning disabilities—before being diagnosed with ADHD; 3) Input from sources outside the primary care setting, such as parents and teachers, must be considered; and 4) Thyroid hormone level tests, brain imaging studies, and other diagnostic tests should not be relied upon when making a diagnosis of ADHD. Despite these stricter guidelines, the committee says, "This clinical practice guideline is not intended as a sole source of guidance in the evaluation of children with ADHD. Rather, it is designed to assist primary care clinicians by providing a framework for diagnostic decision-making."

AUTISM: MORE EVIDENCE BACKS EARLY INTERVENTION

In a new study, researchers at Yale University believe they have uncovered why people with autism show little interest in or are unable to recognize other people's faces. For the study, Dr. Robert T. Schultz and his research team used magnetic resonance imaging to follow the brain activity of 14 study participants with autism and Asperger's syndrome—a related disorder—while they were shown pictures of faces. (Two control groups also participated, in which none of the participants had any disorder.) During the face discrimination sessions, the study shows that in the group with autism or Asperger's, there was little activity in the part of the cerebral cortex that processes faces (fusiform gyrus [FG]). However, in the adjacent area of the brain (posterior inferior temporal gyri [ITG]), where objects such as cars and boats are processed, high activity was reported. (In both control groups, none of the participants showed any brain activity in the ITG [object processing area] during the face discrimination exercise.) Says Dr. Schultz about the study results, "This finding is very compelling since it fits with our clinical experience of autism." (People with autism and Asperger's syndrome show very little interest in people.) But an understanding of the neurological processing of socially important information, according to Dr. Schultz, "will undoubtedly bring us closer to identifying etiologies, as well as effective treatments." The team concludes that early detection of autism becomes even more critical while a child's brain is still forming. This study was published in the April 2000 issue of *Archives of General Psychiatry*.

"Over a Quarter Century of Caring"
WWW.EPLIBRARY.COM

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AUTISM

PRESCHOOL EDUCATION PROGRAMS FOR CHILDREN WITH AUTISM **NEW!**
SANDRA L. HARRIS AND JAN S. HANDLEMAN
An especially helpful text for those who are considering creating a classroom to serve these children. It is also a checklist to ensure that the services currently offered are state of the art.
PE145AT **$31.00**

KEYS TO PARENTING THE CHILD WITH AUTISM **NEW!**
MARLENE TARG BRILL
An explanation of what autism is and how it is diagnosed. You get advice on identifying resources, working with the therapeutic community, as well as helping a child with autism develop to their potential.
BA103AT **$6.95**

BEHAVIORAL INTERVENTION FOR YOUNG CHILDREN WITH AUTISM
[illegible]anual for Parents [illegible]fessionals **NEW!**
C[illegible]RINE MAURICE, ET AL.
A [illegible]al with a wealth of practical information for parents, professionals, and others concerned with helping children with autism. Contains stories of those who have benifited from behavioral interventions.
PE166AT **$37.00**

CEREBRAL PALSY

CEREBRAL PALSY **NEW!**
MERLIN J. MECHAM
A concise and comprehensive examination of a cluster of developmental motor speech disorders that have come to be classified under cerebral palsy. Provides up to date coverage of clinical problems that are faced.
PE180CP **$26.00**

CEREBRAL PALSY
A Complete Guide For Caregiving
F. MILLER, M.D. & S. BACHRACH, M.D.
Offering sound professional advice with a caring commitment to do what's best for a child with cerebral palsy.
MI150CP (HARD COVER) **39.95**
MI151CP (SOFT COVER) **18.95**

VISUAL IMPAIRMENTS

TRANSITION ISSUES RELATED TO STUDENTS WITH VISUAL DISABILITIES **NEW!**
JANE N. ERIN AND KAREN E. WOLFFE
An explanation and analysis of the critical areas in the lives of those with visual impairments, such as transportation, academics, employment and recreation.
PE168VI **$8.00**

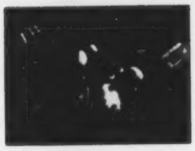
ATTENTION DEFICIT

ADHD HANDBOOK FOR FAMILIES
A Guide to Communicating With Professionals
PAUL L. WEINGARTNER
This empowering book gives families practical concrete know how. It illustrates how to develop behavior modification plans, decide about medication, and how to work with clinical and education professionals for effective interventions.
CW173AD **$20.95**

ATTENTION DEFICIT HYPERACTIVITY AND LEARNING DISORDERS
Questions & Answers
J. GORDON MILLICHAP, MD
Written for parents, layman, teachers and student, and the psychologist or pediatrician. Questions are those most frequently asked supported by answers both general in nature and detailed for the most demanding. Includes Comorbid tics, tourette syndrome
PK100LD **$14.95**

ATTENTION DEFICIT/HYPERACTIVITY DISORDER IN THE CLASSROOM
A Practical Guide for Teach~~ers~~ **NEW!**
CAROL A. DOWDY, ET AL.
A complete guide on how to deal effectively with students who have attention deficits in their classroom. Teachers will learn effective tools to reach students who are often 'lost' in class.
PE149AD **$29.00**

LEARNING DISABILITIES



I WISH I COULD FLY LIKE A BIRD
Audio Tape and Book
KATHERINE DENISON
Children who have been taunted for being different, who have ever felt embarrassed socially, who have resorted to bravado in the face to shame will understand Chic L Dee, a boy bird who discovers his talents; trusts his intuition; and finds his own way.
EXCEPTIONAL PARENT REVIEWED THE BOOK IN THE 3/98 ISSUE.
WCE001LD **$17.95**

PROFILES OF SUCCESS
Successful Adults Achieving with Learning Disabilities **NEW!**
Meet three exceptional adults with learning disabilities who have achieved success, and hear how they struggled and overcame obstacles to choose career paths that best suited their strengths.
LD300LD **$99.00**

LEARNING DISABILITIES IN ADULTHOOD
Persisting Problems and Evolving Issues **NEW!**
PAUL J. GERBER AND HENRY B. REIFF
A comprehensive overview providing in depth coverage of three broad areas--educational, social/emotional, and vocational--reminding you of the myriad of implications learning diabilities have beyond High School.
PE161LD **$38.00**

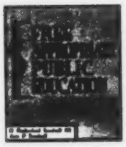
CANCER

CHILDHOOD LEUKEMIA
A Guide for Families, Friends, and Caregivers **NEW!**
NANCY KEENE
The definitive source of information on childhood leukemia that includes information on treatments, advice on how to cope with procedures, as well as stories from families that have already gone down this path.
OA104CN **$24.95**

CHILDHOOD CANCER
A Parent's Guide to Solid Tumor Cancers **NEW!**
HONNA JANES-HODDER AND NANCY KEENE
A guide filled with medical facts that are simple explained, advise that eases daily lives, and tools to help parents become stronger advocates for their child.
OA002CA **$24.95**

EDUCATION

ACTION FOR INCLUSION
How to Improve Schools By Welcoming Children with Special Needs Into Regular Classrooms
O' BRIEN, ET AL.
An extraordinary plain language guide to inclusion. Provides a clear presentation of the values behind full inclusion and outlines a sensible series of actions that can be followed to make full inclusion a reality. **NEW!**
IP700ED **$15.00**



FREE APPROPRIATE PUBLIC EDUCATION
The Law and Children with Disabilities
Sixth Edition
H. RUTHERFORD TURNBULL III AND ANN P. TURNBULL
This resource covers the six principles of the Individual with Disabilities Education Act of 1997. Includes detailed analysis of the most important cases affecting special education law. Covers legislation, case law techniques, due process, and more.
LV140ED **$66.00**

PSYCHOEDUCATIONAL ASSESSMENT OF STUDENTS WHO ARE VISUALLY IMPAIRED OR BLIND **NEW!**
Infancy Through High School
SHARON BRADLEY-JOHNSON
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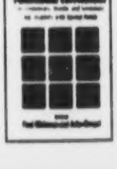

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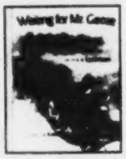

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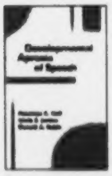

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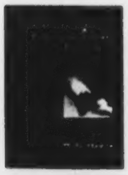

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Alliance for
Technology
Access

Who are we?

The Alliance for Technology Access (ATA) is a diverse group of people. We have become connected and interrelated by our search for technologies to support our dreams. We are people with disabilities, children and adults, family members and friends, teachers and therapists, employers, service providers, technology vendors, professional organizations, and community agencies. We come from all over the United States, from small towns to urban centers. We cross age, ethnic, and ability/disability lines. We represent a growing community of people across the country and around the globe who are employing the tools of technology and reaching new levels of satisfaction. We did not choose technology because we were intrinsically interested in it; we became users of technology because it allowed us to become what we wanted to be: teachers, communicators, artists, composers, students, engineers.

We are connected by a strong belief in the vast potential of people with disabilities to use technology to achieve their dreams, and by a profound commitment to bring the benefits of technology to people who have historically been excluded from the American dream. We have been through the process of trying to understand a bewildering and complex field. We have searched for expertise and support and have created an organization that bonds us to one another and to all people looking for similar answers and support.

The Alliance for Technology Access is a collaborative, energietic community of people redefining what it means to have a disability. Having a disability no longer has to mean that things cannot be done—it means that we can find new ways to get them done. The Alliance is made up of expert advocates dedicated to pushing the limits of convention—people who ask not whether something can be done, but how it can be accomplished. We share your challenges and frustrations. We believe in every person's right to be productive and independent and to achieve his or her desired quality of life. And we believe the most noble application of technology is to support those rights.

The Alliance was created to demonstrate how technology can transform limitations into opportunities. We work toward this goal by providing access to assistive technologies and related services that enable people to achieve productivity, independence, and success according to their needs and interests.

The ATA has rapidly grown from a small group of parents, consumers, professionals, and vendors to become one of the nation's most effective efforts devoted to enabling people with disabilities to gain access to the full benefits of technology. And public demand for services continues to grow at a rapid rate; the number of individuals crossing the resource center thresholds, for example, went from 20,000 in 1987 to over 100,000 today.

People with disabilities must be at the center of the learning and decision-making process. We take a new approach to service, both at our centers and in our book, *Computer Resources for People with Disabilities* (see this month's Book Notes for an excerpt), that varies from the standard, professionally driven model that assumes the "experts" know what's best for you. We believe that we as individuals know what we need—that a team supported by professional resources can help guide people with disabilities seeking access to technology.

ATA—A nonprofit organization

The ATA head office in San Rafael, CA, provides technical assistance, training and support to:

- 40 independent, community-based, consumer-driven technology resource centers around the country that serve consumers and their families as well as schools, health professionals, and community organizations;
- 80 vendors of conventional and assistive technology; and
- A growing number of allied organiza-

The Alliance is made up of expert advocates dedicated to pushing the limits of convention—people who ask not whether something can be done, but how it can be accomplished.

tions and individuals working to increase access to technology for people with disabilities.

ATA's vision is of a future in which technology is flexible, inexpensive, accessible, and seamless in connecting us all to the world.

The ATA national office also provides:

- Training sessions for disability and health-related professionals;
- Consultations to corporations about the kind of technology tools needed by people with disabilities;
- Teams of consumers and health professionals to test hardware and software;
- A telecommunications link throughout the world on its Web site;
- A nationally acclaimed resource guide on assistive technology; and
- Advice and counsel for those wishing to promote technology access to all people.

ATA Resource Centers provide:

- A place where family members, educators, employers, legislators, and people with disabilities can explore computers, telecommunications systems, and adaptive devices;
- Access to experts in the use of conventional and assistive technology;
- Direct service to people with disabilities each year;
- Technical assistance to teachers, service providers, and therapists;
- Training sessions for 600 school districts and 180 colleges; and
- Information about resources available to 1,700 community organizations. ■

The ATA's annual conference, "Institute 2000," will be held October 15-17, 2000, in Minneapolis, MN. Membership in ATA is required in order to participate. To find out how to become a member, obtain more information on the ATA, or to find a Resource Center near you, contact:

Alliance for Technology Access
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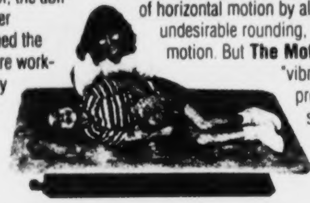
San Rafael, CA 94901
(415) 455-4575
E-mail: ATAinfo@ATAccess.org
http://www.ATAccess.org



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There are more RedBarn products on the way that will provide patients with unique solutions for their therapeutic and mobility needs. In fact, our best product ideas come from patients and their families. Do you have an idea for a product to fulfill an unmet therapeutic need? Please get in touch. We'd love to hear from you!

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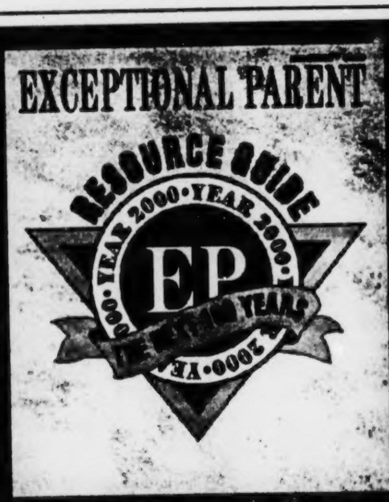

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familiar faces

MARQUIES

According to his mom, Adriane, **Marquies David Winston,** 5, has a face too lovable to forget! Marquies has cerebral palsy, developmental delay, and cortical blindness. He loves his friends and family, and enjoys riding in the car, traveling, and smiling at all the women who call him a "cutie pie." Marquies attends a regular public school and lives with his mom and dad, Russell, in Columbia, SC.

FAITH & WILL

Hang a right up ahead! **Faith Beurrier** (right), 20 months, and her friend **Will Lienemann,** 2, go for a spin! Will and Faith both have Down syndrome and receive speech, physical, and occupational therapy, as well as early intervention. Faith lives in Stuart, FL, with her mom, Paulette, dad, Jim, brother, Tim, 20, and sister, Joy, 16. Will, his mom, Deanne, dad, Clark, and sister, Rachel, 5, have recently moved to Indianapolis, IN. Faith's mom says that Faith misses her playmate: "They got along really well and had fun."

JUSTIN

A budding equestrian, **Justin Anthony Litke,** 4, enjoys horseback riding! Justin, who has cerebral palsy, loves computer games, books, and anything with wheels! His mom, Ann, says he's a very affectionate little boy with a great sense of humor. Justin attends pre-school four days a week and lives in Maple Grove, MN, with his mom, dad, Chuck, and brother, Adam, 7.

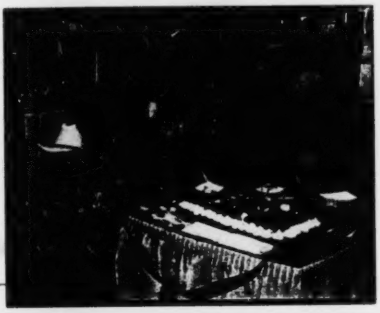
Would you like to share a favorite candid snapshot or slide of your child and/or family with other readers of EXCEPTIONAL PARENT? Send it to: Readers' Photos, *EXCEPTIONAL PARENT*, 555 Kinderkamack Road, Oradell, NJ 07649-1517. (Please do not send originals or "one-of-a-kinds" as we regret that **photos cannot be**

DANIEL

Daniel Matthew Ponsot (right) 12, takes a dip with **Keith Vancott**, a family friend. Daniel has cerebral palsy and mental retardation. He attends junior high school in a special program. Daniel loves to swim, and takes private swimming lessons at the local YMCA. He also enjoys watching Barney and Sesame Street videos. Says his mom, Sandy, "Daniel always tries his best in all he does, and we are all proud of his accomplishments." Daniel lives in Bellerose Manor, NY, with his mom, dad, Antoine, and dog Sadie Baby.

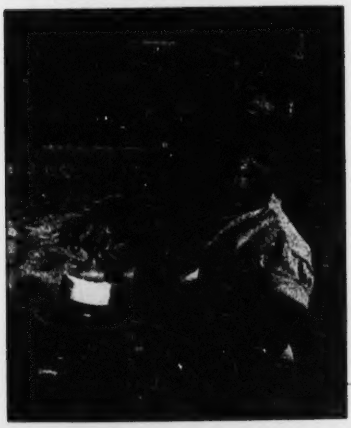
JACY

Jacy Hoagland, 8, helps celebrate Buffalo Bill's birthday! Jacy has developmental delays. She uses a wheelchair and a walker, communicates using some sign language, and is practicing with an adaptive communication device. Jacy is mainstreamed in the second grade with an aide. She loves skiing, playing with dolls, listening to music, and traveling. According to her mom, Patty, Jacy is a happy, healthy, and busy little girl. Jacy lives with her mom and dad, Bill, in Golden, CO.



SHANNON

This picture of **Shannon Bauer** hanging out at the beach was taken when she was 18 months old. Shannon, now 2, has Down syndrome, and receives occupational, speech, and physical therapy. She also takes dance classes and goes to "kindermusic." Shannon loves to run around, swim, and listen to music. Barney is also a favorite. Shannon lives in Manasquan, NJ, with her mom, Jackie, dad, Tommy, and two older brothers, Austin, 13, and Ian, 12. Her mom reports that Shannon is going be a big sister in October!



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returned.) On a separate sheet of paper, write your child's full name, age at the time the photo was taken, address and daytime phone number. Please identify everyone in the photo. If you like, you can also write a few sentences about your child. Then look for a familiar face in an upcoming issue!

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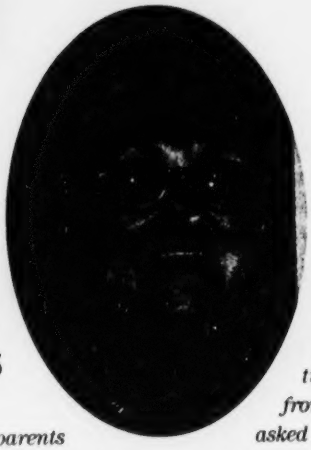
Circle #49

Martha Ziegler: Parent, Child Advocate, Founder of the Federation for Children with Special Needs



PART 1

In less than 30 years, the parents movement has played a crucial role in creating the legislation and attitude changes that have considerably enhanced the opportunity for all children with disabilities to live a full life. In this issue, we honor one of those pioneer parents, Martha Ziegler, the founder and executive director for 23 years of the Federation for Children with Special Needs. Among Martha's many activities through the Federation was the pilot project that would eventually give rise to the federally funded Parent Training and Information (PTI) Centers, the network of parent-run programs that provide "training and information to meet the needs of parents of children with disabilities" throughout the U.S. and in American Samoa.

This year, the Federation marks its silver anniversary and though previously recognized as one of our "Exceptional People" (January 1999) for her outstanding contributions, Martha and the work of the Federation are worthy of praise as they continue to lead the way for innovative ideas and programs. The following is excerpted from the Federation's publication, "NewsLine," which asked Martha to reflect on the early days. Next month, in a one-on-one interview with EP, Martha shares the most important lessons she learned in promoting the growth and independence of all children with disabilities.

In her efforts to achieve quality educational opportunities first for her daughter, Martha Ziegler furthered a movement that would begin to change forever the life possibilities for children with disabilities in the United States and around the world. At the heart of all of Martha's mothering and advocacy is a vision of respect, dignity, love, and human rights for all human beings.

"When our family moved to Lexington, Massachusetts, in 1971,"

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Martha explains, "we decided it was time for Mary Ann, our daughter with autism and all the urgent perplexing needs that come with autism, to go to public school. If our taxes were paying for our son Fred's education, why should they not also pay for Mary Ann's schooling?" Up to that time Mary Ann, then 7, had legally been denied public education in Connecticut and New York. Had the Ziegler family stayed on Long Island, Mary Ann would have gone to school in a converted warehouse in the next county, along with 150 children much like her.

Unwilling to compromise her own vision for her daughter, Martha realized she could not afford to sit back and wait for things to change. At a parent meeting she heard about an amazing bill that had been filed in the Massachusetts Legislature, a bill that, in Martha's words, "would mandate locally supported education for all children with disabilities, with individually tailored programming and meaningful parental input."

Martha became a prime force lobbying for passage of the new law, a fixture in the halls of the State House. She went on to become co-chair of the Coalition for Special Education. The Coalition was a varied collection of 42 organizations, from disability groups to the Massachusetts PTA and Greater Boston Chamber of Commerce, that lobbied for the law. These lobbying efforts succeeded with the enactment of Chapter 766 in 1972, which went into effect in September 1974. It is one of the nation's first comprehensive laws mandating individualized education for the state's children with disabilities. Martha and other parent leaders realized that making the promise of the law a reality in the lives of real children would require that parents be informed and empowered. Large numbers of parents would need to learn about the law. They would also need the support and encouragement of other parents to change not only their expectations for their children, but to have the courage to insist that schools and society see their sons and daughters in a new light as well. To that end, Martha led the effort to pull the parent-run, disability-specific groups together to form their own organization, the Federation for Children with Special Needs. With a pilot grant from the Federal Office of Education, the Federation opened an office in July 1975. It was only the beginning. ■

Adapted from NewsLine, Winter 2000. For more information on the Federation, contact them at 1135 Tremont St, Ste 420, Boston, MA 02120; Telephone: (617) 236-7210; (800) 331-0688 (in MA); Fax: (617) 572-2094; Web site: http://www.fcsn.org. For a PTI in your state, contact the PACER Center at (888) 248-0822 (Voice); (612) 827-7770 (TDD); or the Web site: http://www.pacer.org.

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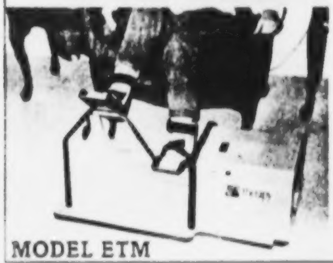

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ask the doctor

Juvenile Arthritis

Early diagnosis and treatment are key to avoiding complications

by John H. Klippel, MD

Q What is juvenile arthritis?

A The word arthritis refers to inflammation (that is, swelling, heat, and pain) to the joints. Arthritis is frequently a chronic illness, meaning that it may last for months or years. Though often associated with aging, arthritis can actually occur as early as infancy.

Juvenile arthritis refers to arthritis, or an arthritis-related condition (rheumatic disease) that occurs by age 15. Nearly 300,000 children in the U. S. have some form of juvenile arthritis. The most common is called juvenile rheumatoid arthritis (JRA).

JRA affects an estimated 30,000 to 50,000 children in the U.S. Although the term JRA brings to mind a single disease similar to "adult" rheumatoid arthritis, it is actually an umbrella term for three forms of childhood arthritis, each with a different pattern and prognosis.

1. Polyarticular (affecting many joints) JRA: This type of JRA affects more than five joints, most commonly the small joints of the hands as well as the knees, ankles, hips, and feet. Joint involvement is usually symmetrical, meaning if a joint on the left side is affected, its counterpart on the right side is affected as well.

Polyarticular JRA has two subtypes. The first is characterized by the presence of "rheumatoid factor" (a type of antibody) and a "genetic type" called HLA-DR4. This form of JRA is often referred to as "seropositive, polyarticular" JRA. The pattern of this subtype resembles adult RA, has the potential to severely damage joints, and often persists into adulthood. In addition to arthritis, children with this form of JRA may develop nodules under the skin or involvement of internal organs.

In the second subtype, children also have multiple joints affected by arthritis (polyarthritis) but do not have a positive rheumatoid factor. This subtype is sometimes referred to as "seronegative, polyarticular" JRA.

2. Pauciarticular (affecting few joints) JRA: This form of JRA generally affects four or fewer joints in an asymmetrical fashion. (That is, if one elbow or knee is affected, the opposite elbow or knee is not.) The joints most likely to be affected are the knees, elbows, wrists, and ankles. This form of JRA has three subtypes.

In the first subtype of pauciarticular JRA, children test positive for "antinuclear antibodies" (autoantibodies that react against the body's own cells) and have a high risk of iridocyclitis, a potentially dangerous inflammation of the eye. In general, all children with JRA are tested for antinuclear antibody (ANA). If the ANA is positive, then evaluation by an ophthalmologist to test for eye complications is important.

In the second subtype, arthritis affects the spine as well as other joints, although spinal involvement may not occur until the child reaches his or her late teens. Children with this subtype may test positive for the HLA-B27 genetic type, which is common in adults with ankylosing spondylitis (a stiffness in the joints and ligaments of the spine that may progress to fusion of the spine). In fact, some doctors refer to this subtype of JRA as "juvenile ankylosing spondylitis."

In the third subtype, children develop arthritis of several joints—most commonly the knee, wrists, or elbows—without spine involvement or eye complications.

3. Systemic Onset JRA: As the name suggests, this form of JRA affects many different body systems and the child may be very ill. Another name for this form of JRA is Still's disease. It often begins with a fever and chills that appear off and on for weeks. These may be accompanied by a rash on the thighs and chest. In addition to inflamed joints, a child may experience enlargement of the spleen and lymph nodes; inflammation of the liver; heart and surrounding tissues; and anemia. There are no subtypes.

Q What causes JRA?

A The cause is not known. There are probably many genetic and environmental causes, such as a virus or bacteria that triggers the disease in children with a genetic predisposition.

Q Who gets JRA?

A Juvenile rheumatoid arthritis can occur in boys or girls of any age, but it tends to peak during the toddler and early-teen years. Certain subtypes are more likely to occur in children of a certain age. Certain types and subtypes are more prevalent in boys than girls, and vice versa. In general, JRA affects more girls than boys.

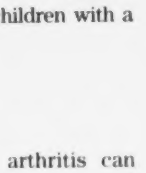
Q How is JRA diagnosed?

A Diagnosing JRA involves a medical history, physical exam, and possibly a number of laboratory tests, including blood tests to measure inflammation and detect antinuclear antibodies, rheumatoid factor, or sometimes HLA-B27.

Ask the Doctor addresses issues of concern to our readers and is usually coordinated on a monthly basis by David Hirsch, M.D., a pediatrician and member of EXCEPTIONAL PARENT's Editorial Advisory Board. Dr. Hirsch is a partner in Phoenix Pediatrics, Ltd., in Phoenix, Arizona, and specializes in treating children who have developmental disabilities and chronic illnesses.

Parents should review any suggestions made in this column with the appropriate professionals. Mention of specific products or medications illustrate suggestions and are not endorsements of any specific products.

Send questions to: Ask the Doctor, EXCEPTIONAL PARENT, 555 Kinderkamack Road, Oradell, NJ 07649-1517, or fax, (201) 634-6570.



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Q Are there other forms of childhood arthritis?

A Many forms of arthritis that affect adults also occur less frequently in children. These include lupus, dermatomyositis, and scleroderma.

Q How does childhood arthritis affect growth and development?

A One of the major problems with JRA is that growth is slowed by the arthritis such that children may end up shorter than their peers. There are several approaches that work to minimize this complication and maintain normal growth. As noted above, glucocorticoids should be used cautiously since they too will impair growth. Most important, early diagnosis and early aggressive treatment to get the arthritis under control quickly are perhaps the best ways to avoid and prevent this complication.

Q What drugs are used to treat JRA ?

A In many ways, JRA is treated similarly to adult RA. Nonsteroidal anti-inflammatory drugs (NSAIDs), including aspirin as well as over-the-counter and prescription drugs, are generally the first line of defense against JRA. If the disease is progressive, the child's doctor may prescribe disease-modifying antirheumatic drugs, such as methotrexate, injectable gold, or the new biologic agent etanercept (Enbrel®), which was recently approved for the treatment of JRA. Glucocorticoids, such as prednisone, are usually reserved for children with severe, progressive arthritis who do not respond to other therapies—or who have internal organ or eye inflammation—because of their potential, at high doses, to stunt growth. ■

This month's guest columnist, John Klippel, MD, is the Medical Director of the Arthritis Foundation. Dr. Klippel has also served as Clinical Director of the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS), an organization of the National Institutes of Health.

For more information, contact:

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E-mail: help@arthritis.org; Web site: http://www.arthritis.org

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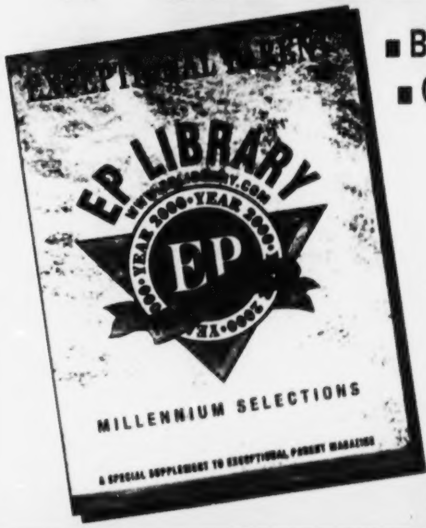

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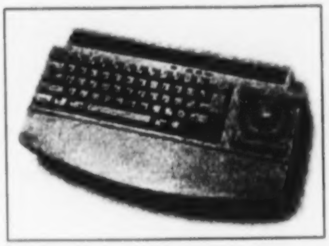

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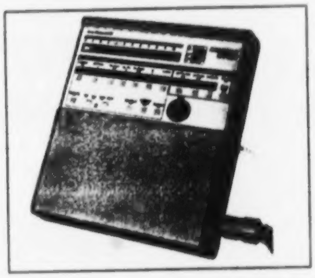

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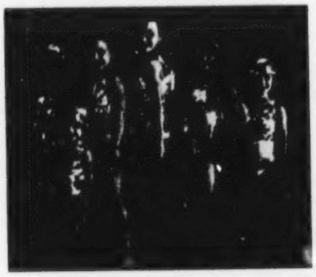

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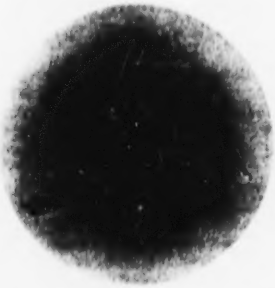

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For more information on these and other assistive devices, or to submit product information for the database (and possible inclusion on this page), contact: **ABLEDATA, 8401 Colesville Rd., Ste. 200, Silver Spring, MD 20910; (800) 227-0216 or (301) 608-8998 (voice); (301) 608-8912 (TTY); (301) 608-8958 (fax); Web site: http://www.abledata.com.**

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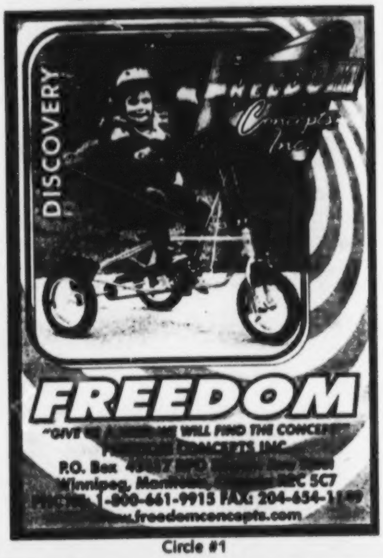
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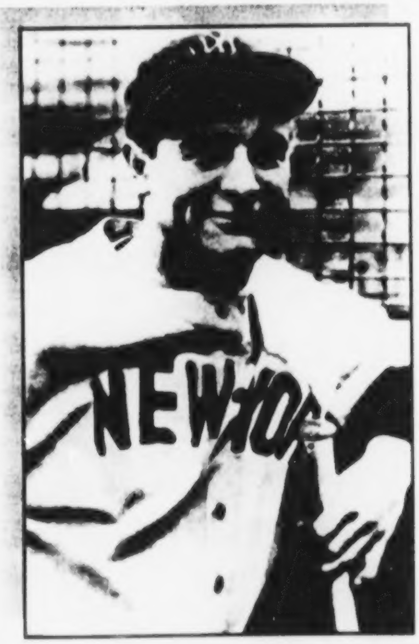

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"Steven is an awesome person who has inspired me to take life one day at a time and not take anything for granted."

I TRUST YOU

by Melissa Scranton

I trust you with my brother,
And I hope that you will see,
Although he may seem confident,
He's as fragile as can be.
If at first he seems unfriendly,
Or he doesn't seem to care,
Remember this is new to him,
He may be frightened there.
If he's quiet and seems to
need someone,
To come and take his hand,
Give him time to get to know you,
Try to understand.
He loves to meet new people,
He's a good friend from the start,
But he's also very sensitive,
And a friend could break his heart.
I wish you knew him better,
To know the things I know,
Just treat him gently like a flower,
And like a flower, he'll grow.
I know I can't be by his side,
Each hour of the day,
I just need reassurance,
That he's going to be okay
I hope you'll grow to love him,
He's a very special boy,
He's always shown me lots of love,
And happiness and joy.
Forgive me if I sound as though
I have so much to request,
My brother means the world to me,
I'll always want what's best.

Melissa Scranton, 16, wrote this poem as an extra credit assignment for her English class. Inspiration for her words came from her brother Steven, 18, who has Down syndrome. Melissa and Steven attend the same high school and share a very close sibling relationship. They often ride bikes together, and Melissa is Steven's buddy on a local Challenger League baseball team. According to Melissa, "Steven is an awesome person who has inspired me to take life one day at a time and not take anything for granted." Melissa and Steven live with their younger brother David and parents, Jean and Steven, in Swampscott, Massachussetts. ■

Take me out to the ball game! Above: Melissa and Steven—baseball buddies, loving siblings. Right: (from left to right) David, Melissa, and Steven find ways to lighten things up to calm the pre-game jitters.

MOM'S TURN

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The Children's Page welcomes contributions from children who have disabilities, their siblings, and their friends. Be creative! Send your stories, photos and/or artwork to: Children's Page, EXCEPTIONAL PARENT, 555 Kinderkamack Road, Oradell, NJ 07649-1517. Be sure to include your name, address, and day-time telephone number! Now on the Web! We will now be including **Familiar Faces** and **Children's Page** on our Web site, www.eparent.com. Please send us your photographs with the understanding that doing so gives Exceptional Parent permission to put the photos on the Exceptional Parent Web site, exactly as they appear in the magazine and with the same text.

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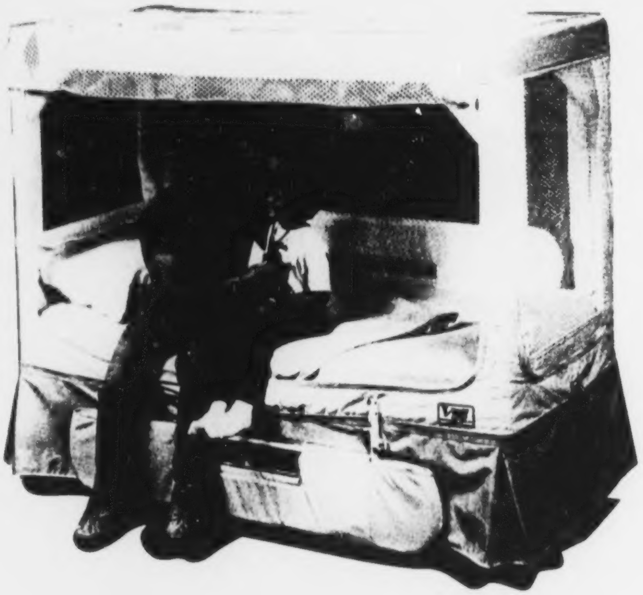

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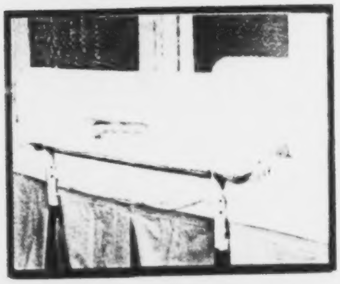

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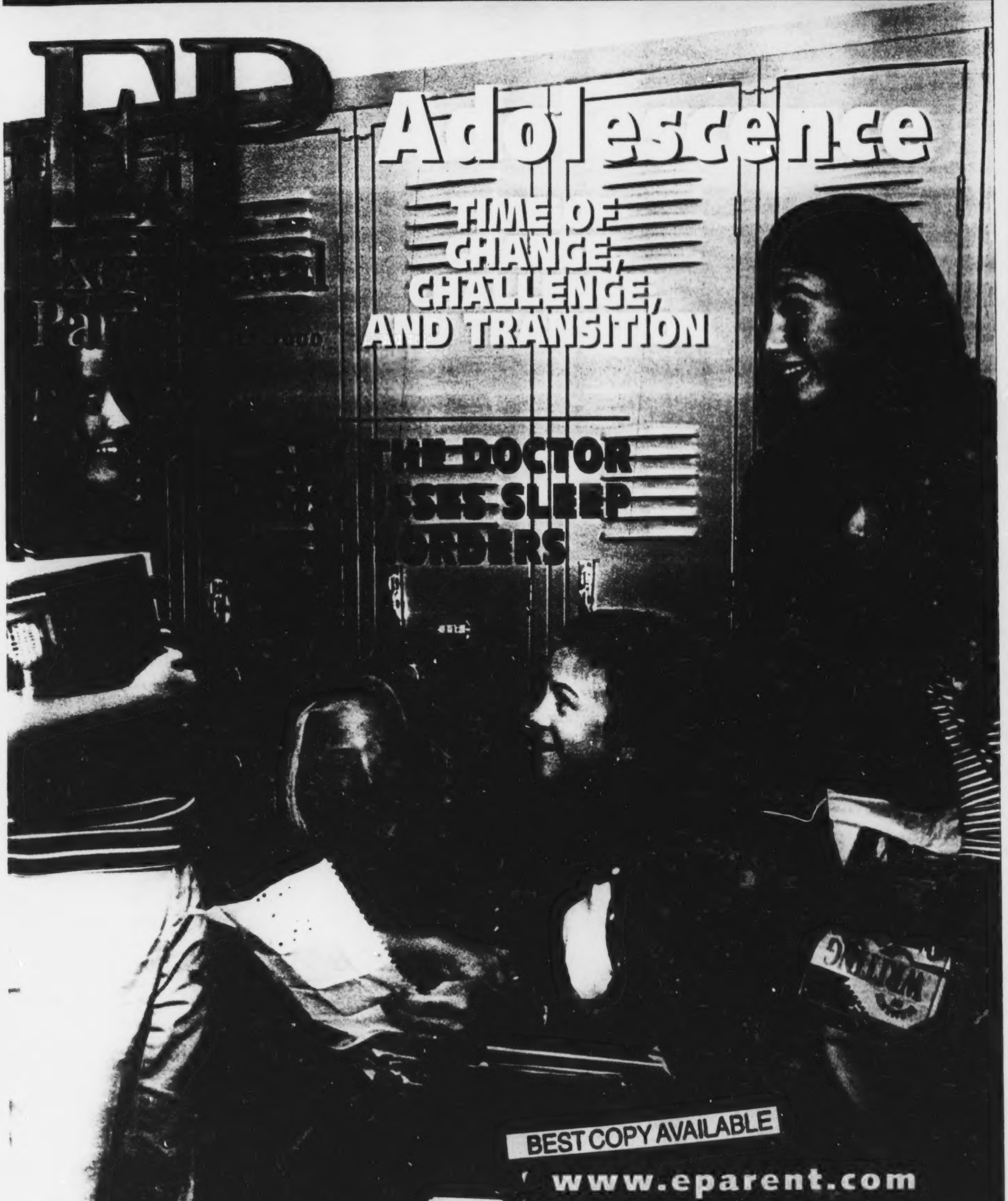

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levocarnitine
Tablets 330mg • Oral Solution 1g/10mL

Please refer to the attached brief summary of prescribing information.

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Carnitor®
levocarnitine

Tablets 330mg • Oral Solution 1g/10mL

CARNITOR® (levocarnitine) Tablets (330 mg)
CARNITOR® (levocarnitine) Oral Solution (1 g/10 mL multidose)
FOR ORAL USE ONLY. Not for parenteral use. Rx only.

BRIEF SUMMARY

The following is a brief summary. Please see package insert for full prescribing information.

CLINICAL PHARMACOLOGY

CARNITOR® (levocarnitine) is a naturally occurring substance required in mammalian energy metabolism. It has been shown to facilitate long-chain fatty acid entry into cellular mitochondria, therefore delivering substrate for oxidation and subsequent energy production. Fatty acids are utilized as an energy substrate in all tissues except the brain. In skeletal and cardiac muscle they serve as major fuel. Primary systemic carnitine deficiency is characterized by low plasma, RBC, and/or tissue levels. It has not been possible to determine which symptoms are due to carnitine deficiency and which are due to the underlying organic acidemia, as symptoms of both abnormalities may be expected to improve with carnitine. The literature reports that carnitine can promote the excretion of excess organic or fatty acids in patients with defects in fatty acid metabolism and/or specific organic acidopathies that bioaccumulate acyl CoA esters.

Secondary levocarnitine deficiency can be a consequence of inborn errors of metabolism. CARNITOR® may alleviate the metabolic abnormalities of patients with inborn errors that result in accumulation of toxic organic acids. Conditions for which this effect was demonstrated are: glutaric aciduria II, methyl malonic aciduria, propionic acidemia, and medium chain fatty acyl CoA dehydrogenase deficiency. Autointoxication occurs in these patients due to the accumulations of acyl CoA compounds that disrupt intermediary metabolism. The subsequent hydrolysis of the acyl CoA compound to its free acid results in acidosis that can be life threatening. Levocarnitine clears the acyl CoA compound by formation of acyl carnitine which is quickly excreted.

Levocarnitine deficiency is defined biochemically as abnormally low plasma levels of free carnitine, (less than 20 μmol/L at one week post term) and may be associated with low tissue and/or urine levels. Further, this condition may be associated with a ratio of plasma ester/free levocarnitine levels greater than 0.4 or abnormally elevated levels of esterified levocarnitine in the urine. In premature infants and newborns, secondary deficiency is defined as plasma free levocarnitine levels below age related normal levels.

BIOAVAILABILITY/PHARMACOKINETICS

In a relative bioavailability study in 15 healthy adult male volunteers CARNITOR® Tablets were found to be bio-equivalent to CARNITOR® Oral Solution. Following the administration of 1980 mg b.i.d., the maximum plasma concentration level (C_{max}) was 80 nmol/mL and the time to maximum concentration (T_{max}) occurred at 3.3 hours. There were no significant differences for AUC and urinary excretion observed between these two formulations.

In the same bioavailability study of 15 healthy adult males, CARNITOR® (levocarnitine) Injection administered as a slow 3 minute bolus intravenous injection at a dose of 20 mg/kg showed that free levocarnitine plasma profiles are best fit by a two compartment model. Approximately 76% of free levocarnitine is eliminated in the urine. Using plasma levels uncorrected for endogenous levocarnitine, the mean distribution half life was 0.585 hours and the mean apparent terminal elimination half life was 17.4 hours following a single intravenous dose.

The absolute bioavailability of L-carnitine from CARNITOR® Tablets and Oral Solution was determined compared to the bioavailability of L-carnitine from CARNITOR® Injection Intravenous in 15 healthy male volunteers. After correction for circulating endogenous levels of L-carnitine in the plasma, absolute bioavailability was 15.1% ± 5.3% for L-carnitine from CARNITOR® Tablets and 15.9% ± 4.9% from the Oral Solution.

Total body clearance of L-carnitine (Dose/AUC including endogenous baseline levels) was a mean of 4.00 L/hr. Endogenous baseline levels were not subtracted since total body clearance of L-carnitine does not distinguish between exogenous sources of L-carnitine and endogenously synthesized L-carnitine. Volume of distribution of the intravenously administered dose above baseline endogenous levels was calculated to be a mean of 29.0 L ± 7.1 L (approximately 0.39 L/kg) which is an underestimate of the true volume of distribution since plasma L-carnitine is known to equilibrate slowly with, for instance, muscle L-carnitine.

L-carnitine was not bound to plasma protein or albumin when tested at any concentration or with any species including the human.

INDICATIONS AND USAGE

CARNITOR® (levocarnitine) is indicated in the treatment of primary systemic carnitine deficiency. In the reported cases, the clinical presentation consisted of recurrent episodes of Reye-like encephalopathy, hypoketotic hypoglycemia, and/or cardiomyopathy. Associated symptoms included hypotonia, muscle weakness and failure to thrive. A diagnosis of primary carnitine deficiency requires that serum, red cell and/or tissue carnitine levels be low and that the patient does not have a primary defect in fatty acid or organic acid oxidation (see Clinical Pharmacology). In some patients, particularly those presenting with cardiomyopathy, carnitine supplementation rapidly alleviated signs and symptoms. Treatment should include, in addition to carnitine, supportive and other therapy as indicated by the condition of the patient.

CARNITOR® (levocarnitine) is also indicated for acute and chronic treatment of patients with an inborn error of metabolism that results in a secondary carnitine deficiency.

CONTRAINDICATIONS

None known.

WARNINGS

None.

PRECAUTIONS

General

CARNITOR® (levocarnitine) Oral Solution is for oral/internal use only.

Not for parenteral use.

Gastrointestinal reactions may result from too rapid consumption of carnitine. CARNITOR® (levocarnitine) Oral Solution may be consumed alone, or dissolved in drinks or other liquid foods to reduce taste fatigue. It should be consumed slowly and doses should be spaced evenly throughout the day to maximize tolerance.

Carcinogenesis, mutagenesis, impairment of fertility

Mutagenicity tests performed in *Salmonella typhimurium*, *Saccharomyces cerevisiae*, and *Schizosaccharomyces pombe* indicate that CARNITOR® (levocarnitine) is not mutagenic. Long-term animal studies have not been conducted to evaluate the carcinogenicity of the compound.

PREGNANCY

Pregnancy Category B.

Reproductive studies have been performed in rats and rabbits at doses up to 3.8 times the human dose on the basis of surface area and have revealed no evidence of impaired fertility or harm to the fetus due to CARNITOR®. There are, however, no adequate and well controlled studies in pregnant women. Because animal reproduction studies are not always predictive of human response, this drug should be used during pregnancy only if clearly needed.

NURSING MOTHERS

It is not known whether this drug is excreted in human milk. Because many drugs are excreted in human milk, a decision should be made whether to discontinue nursing or to discontinue the drug, taking into account the importance of the drug to the mother.

PEDIATRIC USE

See Dosage and Administration.

ADVERSE REACTIONS

Various mild gastrointestinal complaints have been reported during the long-term administration of oral L- or D,L-carnitine; these include transient nausea and vomiting, abdominal cramps, and diarrhea. Mild myasthenia has been described only in uremic patients receiving D,L-carnitine. Gastrointestinal adverse reactions with CARNITOR® (levocarnitine) Oral Solution dissolved in liquids might be avoided by a slow consumption of the solution or by a greater dilution. Decreasing the dosage often diminishes or eliminates drug-related patient body odor or gastrointestinal symptoms when present. Tolerance should be monitored very closely during the first week of administration, and after any dosage increases.

Seizures have been reported to occur in patients with or without pre-existing seizure activity receiving either oral or intravenous levocarnitine. In patients with pre-existing seizure activity, an increase in seizure frequency and/or severity has been reported.

OVERDOSAGE

There have been no reports of toxicity from carnitine overdosage. The oral LD_{50} of levocarnitine in mice is 19.2 g/kg. Carnitine may cause diarrhea. Overdosage should be treated with supportive care.

DOSAGE AND ADMINISTRATION

CARNITOR® (levocarnitine) Tablets.

Adults: The recommended oral dosage for adults is 990 mg two or three times a day using the 330 mg tablets, depending on clinical response.

Infants and children: The recommended oral dosage for infants and children is between 50 and 100 mg/kg/day in divided doses, with a maximum of 3 g/day. Dosage should begin at 50 mg/kg/day. The exact dosage will depend on clinical response.

Monitoring should include periodic blood chemistries, vital signs, plasma carnitine concentrations and overall clinical condition.

CARNITOR® (levocarnitine) Oral Solution.
For oral use only. **Not for parenteral use.**

Adults: The recommended dosage of levocarnitine is 1 to 3 g/day for a 50 kg subject, which is equivalent to 10 to 30 mL/day of CARNITOR® (levocarnitine) Oral Solution. Higher doses should be administered only with caution and only where clinical and biochemical considerations make it seem likely that higher doses will be of benefit. Dosage should start at 1 g/day, (10 mL/day), and be increased slowly while assessing tolerance and therapeutic response. Monitoring should include periodic blood chemistries, vital signs, plasma carnitine concentrations, and overall clinical condition.

Infants and children: The recommended dosage of levocarnitine is 50 to 100 mg/kg/day which is equivalent to 0.5 mL/kg/day CARNITOR® (levocarnitine) Oral Solution. Higher doses should be administered only with caution and only where clinical and biochemical considerations make it seem likely that higher doses will be of benefit. Dosage should start at 50 mg/kg/day, and be increased slowly to a maximum of 3 g/day (30 mL/day) while assessing tolerance and therapeutic response. Monitoring should include periodic blood chemistries, vital signs, plasma carnitine concentrations, and overall clinical condition.

CARNITOR® (levocarnitine) Oral Solution may be consumed alone or dissolved in drink or other liquid food. Doses should be spaced evenly throughout the day (every three or four hours) preferably during or following meals and should be consumed slowly in order to maximize tolerance.

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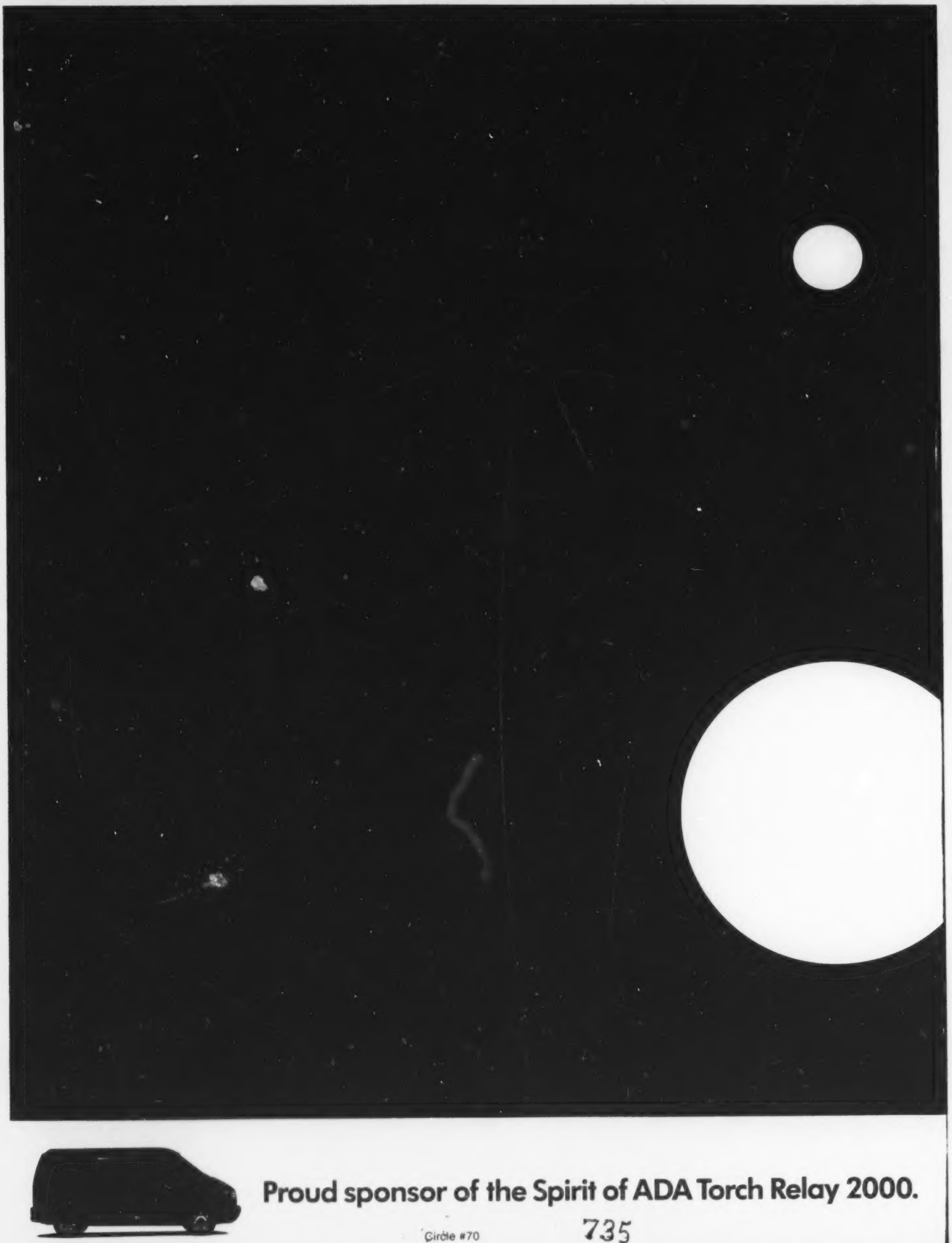

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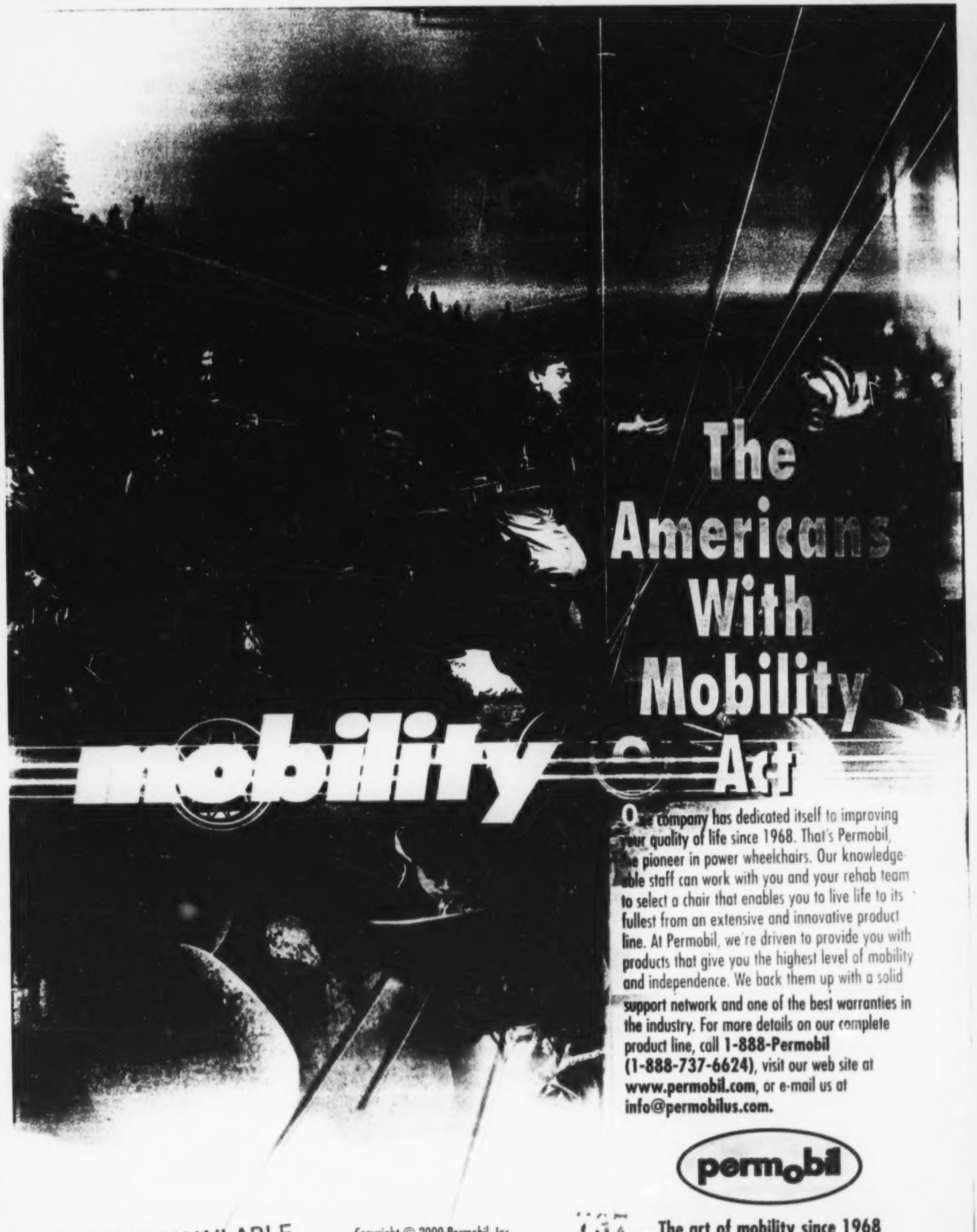
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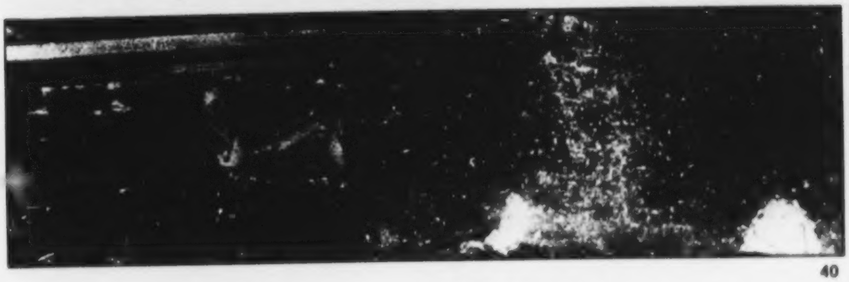
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- *To reach out to mothers and fathers of children and young adults who have disabilities and special healthcare needs.*
- *To empower parents and professionals by providing practical information and emotional support.*
- *To appreciate that parents are the most important experts in the lives of their children.*
- *To energize parents and professionals.*
- *To share ideas and experiences so parents, professionals, people who have disabilities, and other advocates can learn from one another and better collaborate to serve all children and families.*

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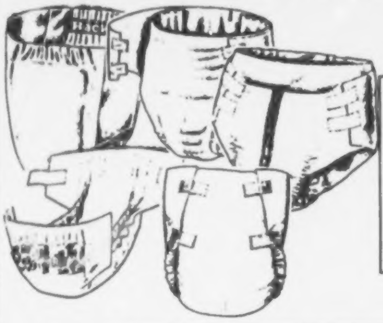

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EXCEPTIONAL PARENT magazine was founded in 1971 by Stanley D. Klein, PhD, and Maxwell J. Schleifer, PhD

MPA

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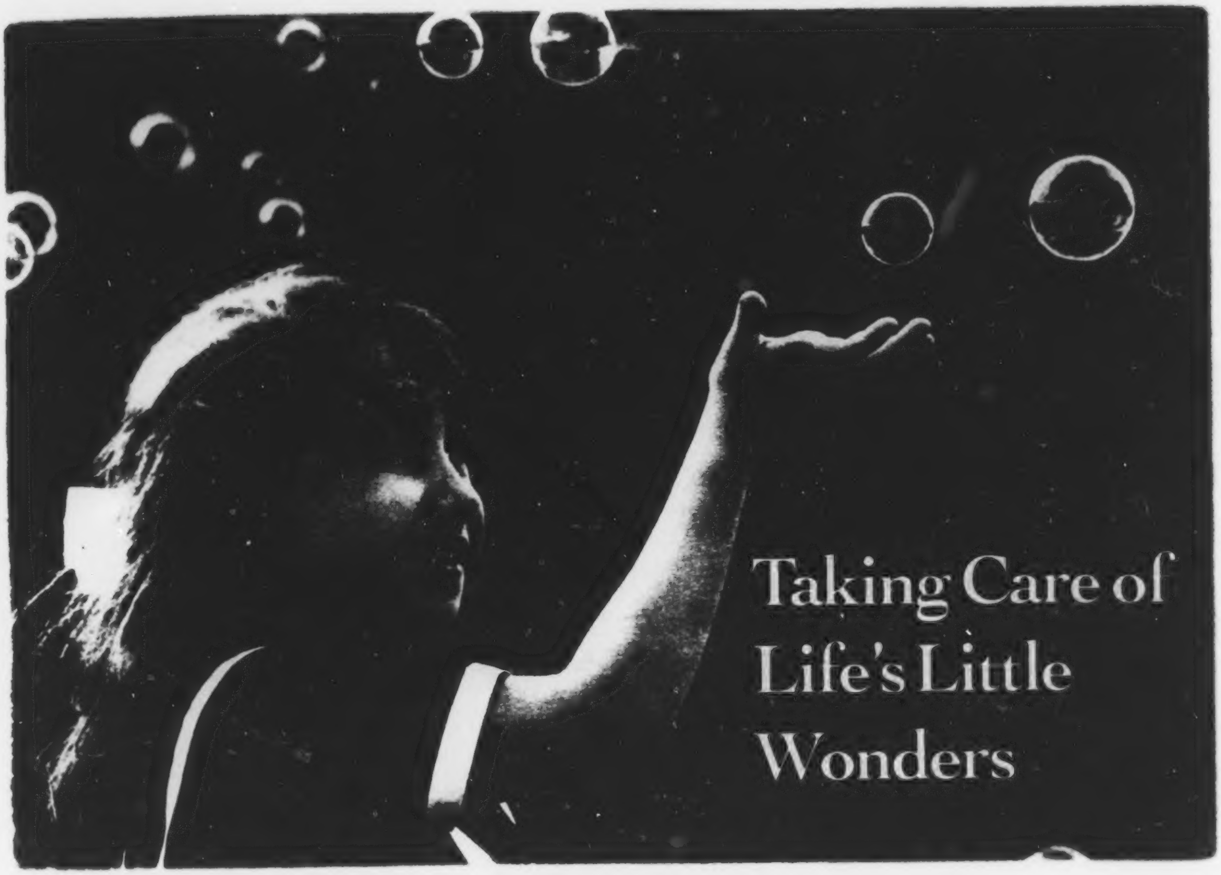

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Circle #23

The Great Divide: Adolescence

Adolescence is a time of great transformation in a child. Parents have long recognized how the biological changes of puberty affect the body in ways that represent more than just the next physical phase. The special problems of identity that come into play can be equally momentous. Questions like "Who am I?" and "What will I become?" emerge as kids begin to ponder more deeply, or for the first time, their surroundings, their friends, and the direction of their lives. Recent data on brain physiology have shown that there are also changes in brain function during puberty.

The major changes that puberty brings on can be especially problematic for youngsters with a disability and their families. Sexual identity and activity that is stirred by these hormonal changes may, at times, go unrecognized by some parents who are overwhelmed with caring for their child. They may not be aware that the lack of intellectual growth and progress in their child does not necessarily hinder the biological changes of adolescence, and they may not pay attention to the child's sexual interests. In "Growing Pains," Vicki Pieser shares a personal, candid anecdote that underlines the importance for parents of making honest admissions about their child's burgeoning sexuality. (Other parents have their own ways of helping their children, and we welcome your own personal stories.)

Maxwell J. Schleifer, PhD
Editor-in-Chief

Children of all ages who are very dependent on others are vulnerable to a multitude of forces within their environment, including sexual abuse. In "An Unacceptable Risk," Jennifer Graham discusses how to recognize the signs of sexual abuse and how to help youngsters avoid it or get support after a traumatic, physical invasion of their bodies.

With newer educational opportunities and greater acceptance from friends and neighbors, more youngsters are mastering the dilemmas of this age. New technology is giving them the ammunition to face the educational challenges that await them. CAST, the Center for Assistive Technology in Peabody, Massachusetts, shares the story of one of their many exceptional students, Mason Barney. Through working with the learning specialists at CAST, Mason began using computer technology to help him develop his skills and understanding of academic materials. Flourishing through high school and college and now in the work force, Mason credits his success to his parents' perseverance in getting him the help he needed.

The transition from grade school to college can be a time filled with anxiety for most young people. In "Passing the Test" by EP staff members Gale Jurasek and David Chamalian, five college students with different disabilities talk openly about how they turned their pre-college anxieties into successes on campus. The struggles for greater independence, mobility, and meeting and making new friends are the focal points of their discussion. Their comments offer a road map for other students.

Swimming is an ideal summertime activity for fun and exercise. Not only does a pool represent a dynamic, low-stress environment for children to "hang loose" and be with friends, it gives them a perfect opportunity to interact with new people and strengthen their social skills. And for a child with a physical disability, the benefits go beyond that. Using water as a medium for physical therapy is a proven way to help children improve their dexterity and gives them the confidence to take on other physical challenges. In "Everybody in the Pool!" by Paula Wanzer, we learn about the many benefits of aqua play for teenagers.

This month we reintroduce our "Rising Star" feature. The feature highlights a young person who is making his or her mark on the world. July's "Star" is 17-year-old Brian Rusconi, a talented, award-winning artist, who has Asperger syndrome. A student at Cardinal Cushing School in Hanover, Massachusetts, he loves to draw pictures for his younger classmates and entertain them with puppet shows using marionettes purchased with the proceeds of his work. In the second part of our focus on EP Hall of Fame honoree, parent advocate Martha Ziegler, she recalls her daughter's educational journey and relates the insights she drew from guiding her through school. Her interview with EP leaves the reader with a firm sense of the importance of recognizing the strengths of each child and insisting educators build on these foundations.

In Memoriam

It is with deep sadness that we announce the passing of advocate and columnist Richard Epstein. As EP's "Health Insurance Troubleshooter," he tackled the questions and problems faced by parents in dealing with insurance and Medicaid coverage. Mr. Epstein also built a reputation as a newspaper columnist in New Jersey with his popular weekly "Living With Disabilities" column. Through his work, he succeeded in helping make life a little easier for those dealing with its greatest challenges. He will be sorely missed.

Welcome

EP is proud to welcome Susan Senator as regular contributing editor. Sue is the mom of three sons, one of whom has autism. We also announce the addition of Arno Fried, MD, FACS, to our Editorial Advisory Board. Dr. Fried is a pediatric surgeon and currently serves as Director of the Pediatric Neuroscience Institute at Hackensack University Medical Center in New Jersey. ■

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Search & Respond

About Search & Respond

Search and Respond is an opportunity for our readers to exchange information about their practical experiences in meeting the everyday challenges of life with a child or adolescent who has a disability. In this column, "S" represents Search letters and "R" represents Respond letters received to a previously printed Search. "Instant S&R" is a new feature which represents e-correspondence we have downloaded from our Web site. All Responds are forwarded to the writers of the original Searches; some are published. Published letters may be edited for purposes of space and clarity. We also expect parents to consult appropriate professionals.

When sending correspondence, please indicate whether it is a Search or a Respond. For Responds, be sure to note in which issue the original Search letter appeared. Please remember to include a phone number on all correspondence, in the event that more information is required. Write to: Exceptional Parent, Attn: Search/Respond, 555 Kinderkamack Rd., Oradell, NJ 07649-1517; Fax to: (201) 634-6570; E-mail to epedit@aol.com; or visit Search and Respond on our Web Site: http://www.eparent.com.

For information about specific disabilities, contact: the National Organization for Rare Disorders (NORD), 100 Rt. 37, PO Box 8923, New Fairfield, CT 06812; (800) 999-6673; (203) 746-6518; Web site: http://www.rarediseases.org. Also, see the "National Resources for Specific Disabilities" directory in Exceptional Parent's 2000 Resource Guide (January 2000, starting on page 30).

Each month, Chris Feudtner, MD, PhD, reviews Search & Respond for accuracy and completeness. Dr. Feudtner is a pediatrician at the Pediatric Care Center of the University of Washington in Seattle, and is currently a Robert Wood Johnson Clinical Scholar. Look for Dr. Feudtner's comments on certain Search & Respond letters.

S

Car seat

My 2-year-old son has spinal muscular atrophy and severe hypotonia (low tone). He is getting too long for a rear-facing convertible car seat. The car seat we have will work if we turn it around but we are concerned about neck and head support when he is facing forward. None of the neck support collars is "transport approved." What have others whose children have low tone done for car seats?

Lisa, via the EP Web site

S

Destructive behavior

My son is 2-years old and was evaluated by our area school district. They were unable to complete any testing, however, because he was pretty upset with the whole process. He throws things, hits, pushes, is very destructive, and acts dangerously without realizing the consequences. Some of this is developmentally appropriate behavior, but the school and I both agreed that he needs further evaluation. He is home with me every day except for one day per week when he is in a daycare program at church. He has had problems there with hair pulling, pushing, hitting, etc., and has to be separated often. We are testing his vision and hearing next. I wonder if any other parents have experienced this in children so young. My son is not talking, but seems bright. I am wondering if we should get help outside of the available county programs.

KH, via the EP Web site

S

Easy exercises for a child with CP

I have a 13-year-old daughter with spastic quadriplegic cerebral palsy. I am in desperate need of ways to help her exercise in order to try and give her some relief from her spasticity. Her muscles are very tight at night, and she is not getting enough physical therapy at school because they are very short-staffed. I have carpal tunnel syndrome and it is difficult for me to maneuver her.

ND, via the EP Web site

S

Communication device

We have a 13-year-old son who has severe spastic cerebral palsy and is also blind. We are interested in a communication device for him. He can reach for a large switch with his hand, but cannot use his fingers. He can move his head—perhaps to hit a switch—and can use his foot a little. We have tried numerous things without much success. Our main problem has been that he is unable to see the communication devices.

LG, South Carolina

EDITOR'S NOTE:

You may want to contact the Communication Aid Manufacturer's Association (CAMA). CAMA hosts workshops throughout the United States year round, highlighting the products of various augmentative and adaptive communication device manufacturers. CAMA can be reached at (800) 441-2262. E-mail: cama@northshor.net. Web site: http://www.aacproducts.org

S

Potty training

My 5-year-old son has autism and is nonverbal. We have been trying to potty train him, but we cannot get him to understand that it is okay to go in the toilet. His receptive language is almost nonexistent, so we cannot explain it to him. Does anyone know how we can get this across to him? We have read tons of books and watched lots of videos, with no success. I would appreciate any input.

KS, Oklahoma

S

Sleep difficulties

I have a 4-year-old son who has cerebral palsy, microcephaly, asthma, reflux, and severe sleep problems. He has an extremely difficult time falling into a deep sleep. He will fall asleep, but wakes up with a scream after about five minutes. This goes on for several hours every night. Once in a deep sleep, he will sleep until morning. I hope someone with a similar experience can suggest a solution.

Tom, via the EP Web site

R

Summer caregiver

JT (June 2000) has a 13-year-old daughter who has speech and

continued on page 19

e good, a hard look at lity.

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Dianna Fitzgerald

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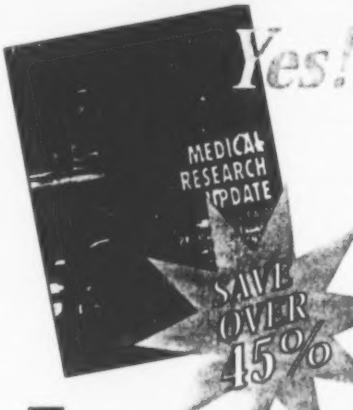

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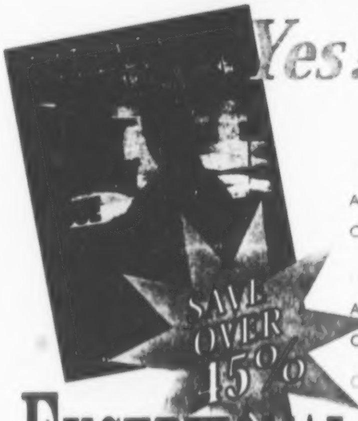

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is the magazine for parents and professionals involved in the care and development of children and young adults with special needs, including Physical Disabilities, Developmental Disabilities, Mental Retardation, Autism, Epilepsy, Learning Disabilities, Perceptual Disabilities, Hearing Impairments, Vision Impairments, Emotional Problems, Chronic Illness.

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continued from page 14

motor delays and some developmental delay. JT is looking for someone who will care for her at home while JT and spouse are at work.

My daughter is 15 and has multiple disabilities. She was diagnosed with a brain tumor at age 7. I need to work full time and need caregivers to be in my home. My employer was willing to place an advertisement in the local paper for me. I conducted interviews over the phone, then set up personal interviews with those I was interested in. I checked references and hired three caregivers. I found additional caregivers through one of the people I hired and they have all been great. Using college students may also be a good idea. The college instructors may know of students who would be interested. PT/OT schools were another option, but I did not have to go that far.

MP, via the EP Web site

R Genetic syndrome

AB (April 2000) has two sons, one with cerebral palsy and leukomalacia, and the other recently diagnosed with myoclonus. AB wonders if the two conditions are related and where to look for more information.

Consider having your sons checked out for leukodystrophy. Contact the United Leukodystrophy Foundation (ULF) for their "Second Opinion" program. Their phone number is (800) 728-5483, E-mail is ulf@tbcnet.com, and their Web site is http://www.ulf.org.

I have two sons who have a form of leukodystrophy that involves myelin loss and calcifications in their brains. The ULF has been very helpful to us. They may be able to help you also.

DM, Michigan

Instant S&R

S Accessible bathroom

We are in the process of designing an accessible bathroom for our 7-year-old son who has multiple severe disabilities. Since our son is completely dependent for care, the bathroom we want to build needs to be tailored for the caregiver as well as the user. We are looking for literature or design concepts for a functional bathroom/shower facility. We appreciate any information or resources. We live in Southern California.

AD, via the EP Web site

R We are in a similar situation with our 4-year-old. We made our own plans with input from a respite center we are involved with here in Massachusetts. We made the bathroom user-friendly for all. It has a pedestal sink, toilet, etc., but we added a row of waist-high cabinetry, which holds supplies and acts as a changing area. This is across from a wheelchair shower, which holds our son's shower chair. We simply pivot from the changing area to the shower. We added a hand-held shower device and hung it where it is convenient to caregivers. The only thing we would add (in our next build) is a jacuzzi tub. We have heard of a device that raises to the height of a wheelchair and then lowers into the tub.

Kris, via the EP Web site

S G-tube

I am the mother of a 5-year-old boy with cerebral palsy, seizure disorder, and developmental disabilities. He does not walk or talk but is a happy, sociable little boy, who gets around by rolling to his destination. Because he is underweight for his age and not a big eater, we have been encouraged to consider a gastrostomy or g-tube (the tube is surgically placed through the abdominal wall into the stomach so nourishment can be infused through the tube directly into the stomach). He currently eats small amounts of mashed-up foods. My concern about a g-tube is that once he is on the feeding tube, he will lose what little ability he has at oral eating. Also, if he is put on a g-tube, will he always need it?

AL, via the EP Web site

R My son is on a g-tube and I, too, was frightened that he would lose the ability to eat on his own. I did not realize that the g-tube feedings help supplement his oral feedings. Now I still feed him by mouth and formula through a g-tube. I love the g-tube now, especially when he gets sick and cannot tolerate oral feedings. I would recommend one to any mom who is having a hard time with feeding or weight gain.

CW, via the EP Web site

S Tangled tubing

I am a community health nurse working with a family with a young child newly diagnosed with Lesch-Nyhan disease (a metabolic disorder that causes a build up of uric acid and severe neurologic disturbances). We are interested in home adaptations for bathing, g-tubes, continuous night feeds, restlessness and getting tangled up in tubing or disconnecting from tubing.

TB, via the EP Web site

R My son is a very active sleeper with a night drip through a g-tube. We have found that if we cut off the lower part of the drip bag's red tip, we can get a much better seal. The red tips on our bags (Kangaroo brand) have several notches. We cut off all but the last two. We then use medical tape to ensure that the port stays shut. We run his tubing up the inside of his pajama leg to ensure that the line stays as far as possible from his neck. My son had a skin reaction to having his tubing taped down, so we started taping the tubing to itself.

KW, via the EP Web site

AUGUST EVENTS CALENDAR

8/4-6 **National Down Syndrome Congress 28th Annual Convention**

Hilton Washington and Towers, Washington D.C.

Topics will include health and medical issues, aging, advocacy and systems change, assistive technology, family issues, and much more.

For registration information call the National Down Syndrome Congress at (800) 232-6372; Fax: (770) 604-9898; E-mail: ndsccenter@aol.com; Web site: http://www.ndsccenter.org.

8/10-12 **Epilepsy Foundation 32nd National Conference**

Omni Hotel at CNN Center, Atlanta, GA

Topics will include school advocacy and IEP planning, financial planning, and seizure management.

For more information on the conference contact the Epilepsy Foundation at (301) 459-3700 or (800) 332-1000; Fax: (301) 577-2684; or Web site: http://www.epilepsyfoundation.org.

8/10-12 **The National Conference of the Foundation Fighting Blindness**

Visions 2000 Breakthroughs and Beyond

Hilton in the Walt Disney World Resort, Orlando, FL

Networking opportunities will abound as will presentations on vision-related topics. Topics will include inherited retinal degenerative disease, research progress and developments, displays of newest and best assistive technology and living aids.

For more information call (800) 683-5555, or go to http://www.blindness.org.

8/11-13 **Abilities Expo**

Rosemont Convention Center

Rosemont, IL

This conference will show the latest in assistive living products and services as well as seminars on insurance coverage, government regulations, and available services. For information call (800) 382-3085; Web site: http://www.abilitiesexpo.com.

The National Institute of Child Health and Human Development (NICHD) offers reading videotapes

The National Institute of Child Health and Human Development (NICHD) has created "When Stars Read," a videotape of children struggling to learn to read and ultimately mastering the skill using a three-part strategy: phonetic awareness, phonics, and whole language. The videotape is available free of charge from the NICHD Clearinghouse. Call (800) 370-2943 or E-mail: NICHDClearinghouse@iqsolutions.com for copies of the tape.

Creative Activities for the Summer

To keep children entertained this summer, Sugar in the Raw® natural sugar has created a colorful brochure filled with fun food activities. The creative projects encourage children to turn everyday foods into artistic masterpieces. Kids can build a Sandcastle Cake using Sugar in the Raw or cruise into the kitchen to make personalized Banana Skateboards. These food-related projects are a good way to teach children basic kitchen skills, such as measuring ingredients and following a recipe, while fostering creativity. For a free copy of Sweet Fun... naturally, just for kids, send a self-addressed stamped business-size envelope to: Sweet Fun, Brooklyn Premium Corp., 60 Flushing Avenue, Brooklyn, NY 11205.

Corrections for JUNE 2000

June's article entitled "Tee Time for All" omitted Abledata's Web site: http://www.abledata.com.

June's "Tech Around the House" incorrectly listed Abledata's phone number. The correct number is (800) 227-0216.

In June's Children's Page, the caption of the second picture misidentifies Jimmy as his father.

WE REGRET THESE ERRORS

Product Recall Information

BOB Trailers Inc., of San Luis Obispo, California, is recalling about 3,700 jogging strollers. The stroller's front wheel connector can crack during use, causing the wheel to separate from the frame. Consumers should stop using the stroller immediately and return it to the store where it was a purchased, or to BOB Trailers for repair. For more information, call (800) 893-2447 or access the company's Web site at http://www.bobtrailers.com/safetynotice.html.

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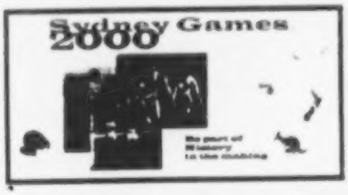
Access Expo 2000, Australia's most comprehensive exhibition of products and services for people with disabilities and their caregivers, will be held October 22-24 at the Australian Technology Park and Convention Centre. The Expo will be held to coincide with the 2000 Paralympic Games in Sydney, Australia. The displays will include travel options, computer technology, mobility aids, vehicle modifications, employment options, and much more. There will be demonstrations of new, adapted leisure and recreational activities, and a diverse range of seminars will be conducted. For further information, contact Julie Stein at +61 3 94151200; E-mail: jstein@paraquad.asn.au; Web site: http://www.paraquad.asn.au/expoi/expo.



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Special Thoughts

by Gay Robin Labrum

A special parent shares what she has learned

Joshua Labrum

I am a special parent. This is because I have a child with special needs. His name is Joshua and he was born on September 10, 1993. He has curly red hair and brown eyes. He has a passion for music, loves to hear me sing, adores his father, James, and his best friend is Eeyore (character from Winne the Pooh). He has epilepsy, cerebral palsy, a severe hearing loss, and a clubfoot (corrected with surgery). He also has a gastrostomy tube for feeding, and a tracheotomy. Joshua's brain injury is due to a knot in his umbilical cord resulting in a lack of oxygen at birth. He does not walk or talk, but he still has the best smile and laugh in the world.

Caring for him sounds like a lot of work, and it is. Some days during his first year-and-a-half seemed overwhelming, but Joshua is good-natured, and that makes a difference. I have always looked for words of wisdom to inspire me and keep me strong in times of adversity, and my experiences with Joshua have taught me a lot. I have some wise words that I would like to share with other parents of special children. I hope they help.

- **Take it one day at a time.** We can only live one day at a time.
- **Keep the faith.** Pray a lot.
- **Cry when you need, as often as you need.** Release your feelings. Talk to someone; friends, family, support groups, and psychologists all help. Talking to a family counselor has opened the communication channels between my husband and me, and we talk much more freely these days.
- **Don't be discouraged! Doctors don't know everything.** Wonderful things still happen. Put these words up in a place where you can read them often.
- **Make sure you get enough sleep.** Nap during the day or get someone to watch your child so you can get some sound sleep. It is essential to your emotional harmony.
- **Pamper yourself.** Treat yourself like someone special. People have said to me, "Take care of that baby!" and I ask them, "What about me?" Take care of yourself. Do not get so caught up in caring for your child that you neglect your inner self. You are important to your child, your family AND yourself, so remember to do things for yourself. Go for a walk; take a bubblebath; start reading your favorite books; start a craft; play the guitar; dance; whatever. Enjoy all the things that make you a special person.
- **Forget the housework.** Care for and enjoy your child NOW. The housework will still be there.
- **Remember the present is precious.** Deal with problems as they arise and don't worry about any possible future problems. Don't get caught up in "what ifs." We can only live with today. Love your child today.
- **Follow your intuition.** Most of the time, parents DO know best, even better than the best doctor. After all, you know your child better than anyone else. Listen to your inner voice.
- **Keep your sense of humor and your perspective.** James and I say that it's not always easy having a special child, but we love that handicapped parking spot!
- **Take time to be alone with your spouse.** At least once a week, for several hours, be with each other. Keep your marriage alive and strong and you can triumph over anything.
- **Keep up-to-date medical records!** This includes evaluations, medication lists, and telephone numbers of key medical and support personnel. ALWAYS take this information with you when your child goes into the hospital. It is invaluable to the doctors and nurses.
- **Ask everyone lots of questions.** Do not be intimidated. This is YOUR child and you have a right to ask and to know what's going on.
- **Do not compare your child with other children.** This is a hard one, but it is necessary. Every child is special. If your child progresses at a different rate, so what? Everything your child accomplishes is wonderful and special, because it takes more effort than that of a "normal" child. Be proud of your child and his accomplishments.
- **Do not feel guilty or ashamed.** Tell people that you have a child with special needs. Be tolerant and open to questions. Help people to understand disabilities.
- **Get to know your child.** Learn to see past the disabilities. James was a little scared to get close to Joshua when he was born, but this past summer, when I was very ill, James had to take care of Joshua and he got to know him as a person. They bonded, and now they are best buddies.
- **Give yourself credit.** Give yourself a pat on the back twice a day.
- **Always hope for the best.** Look for the positive.
- **Never give up.** Your child will progress to his highest skills as long as you are there to stimulate, give encouragement and love.
- **Don't be intimidated by therapists.** They are there to give you sug-

gestions, so talk with them. Tell them how YOU are feeling and what your strengths and limitations are. Do what you can during the day and be glad for what you accomplished. Don't feel guilty for what you didn't do. You can only do so much therapy. You must be a loving parent first. Perform bits and pieces of therapy throughout the day and have fun with your child.

- **Some days, just do the minimum.** You may be exhausted and stressed and all you can do is the minimum. So, DO the minimum—and nothing else. When I have been up several times the previous night I get very tired and usually spend the next day trying to get extra sleep in between caring for Joshua. When I am emotionally drained, it's all I can do to take care of Joshua and nothing else. I've learned that it's okay. You do not have to be "super parent." You are human.
- **Gain strength from your child's inner strength.** A mother once told me, "If my daughter can go to therapy and not cry, so can I." My son Joshua is a fighter. He wouldn't have survived this long if he wasn't. He is a strong child, and we aren't giving up.
- **Treat your child the way you would want to be treated yourself.** Then you will know you have done your best.
- **Be glad you have a child.** There are some couples who don't have any children and might be jealous. Remember the adage, "The grass is always greener on the other side of the fence." Be glad for what you have.
- **Don't neglect your pets.** Give them attention, and help them to know your child, too. After all, they are a part of your family and they can help stimulate the child. Joshua has two older "brothers," the cat and the dog.
- **Savor the special moments.** The first time Joshua cuddled in my arms, I felt his contentment and I felt such love for him it was just wonderful. A bond is created that cannot be broken and will only grow stronger with time.
- **Be patient and gentle with your child.** Your child did not ask to have a disability. Don't take your frustrations out on your child.
- **Notice the beauty in the world.** Don't get so caught up in caring for your child that you forget everything else. Be aware of the peace that can be found in seeing a glorious sunset, smelling a beautiful flower, the coolness of a rain shower, and even the smile of a stranger. Share the world's beauty with your child.
- **Be happy.** Accept that your life will be different, but no less wonderful than anyone else's life. Life is a journey and an adventure, not a destination. It is what YOU make it. Learn to view your child's problems as obstacles to be overcome. James and I say that Joshua's life is an obstacle course, and we will help him run it.
- **Make note of your own insights.** As you grow with your child, you will find your own personal bits of wisdom. Write them down so you can read them often. They will keep you strong.

These are some of the thoughts that have helped me through the day more than once. We have a lifetime of Joshua ahead of us, and we will collect more wise words of courage and fortitude. Joshua is a very happy boy and making progress every day. Life will not always be easy, but it will never be dull or boring. We are on an adventure through life with him, and that is a pretty good place to be. I am content. I am happy. I am a special parent. ■

Gay Robin Labrum and her family make their home in Colorado.

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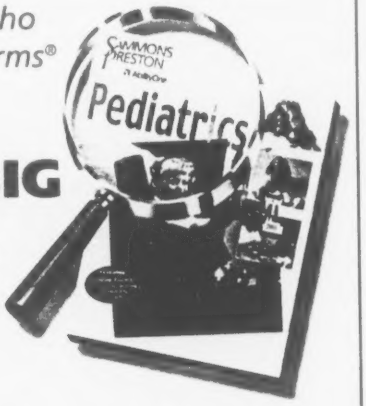

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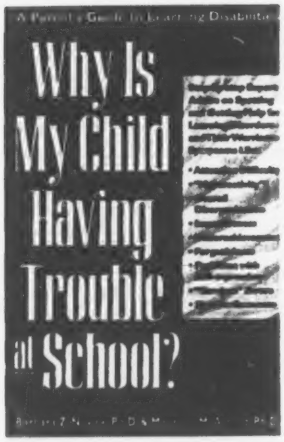
book notes


A Parent's Guide to Learning Disabilities
Why Is My Child Having Trouble at School?

WHY IS MY CHILD HAVING TROUBLE AT SCHOOL?

Barbara Z. Novick, PhD, and
Maureen M. Arnold, PhD
Published by G.P. Putnams Sons,
New York
Available through the EP library
(800) 535-1910.
Code: GP8174LD
Cost: $13.95 plus shipping and handling.

Using observations of students as a background, this book lets parents know how to spot some common signs of learning problems and how to follow up. Below are excerpts covering things that signal a learning problem, parent teacher conferences, teacher observations, and some questions parents may want to ask:

Signs of a Learning Problem

- "Overall disorganization. Papers are crumpled, homework is sloppy, library books are lost, class notes are all over the place.
- "Careless" errors. There are misspelled words, misread instructions and computation signs, misheard directions.
- A know-it-all facade. When asked how today's test went, the child's usual answer is "It was easy." A new book is generally "boring." Homework is usually "all done" in what seems to be too short a time.
- Underachievement. There are clear signs of good intelligence coupled with equally clear signs of serious difficulty in some or several academic areas.
- Forgetfulness. "I forget" is his favorite phrase. When asked about his history test or science assignment, or what his teacher said about some particular topic, he says, "I forget."
- Refusal to do schoolwork. The child's learning difficulty may result in his refusal to perform in school or to do his homework. He may hand in half-done work or study only part of the test material.
- Slow performance. The child takes an excessive amount of time to complete homework and rarely finishes in-school work.

"Other signs that indicate that a child has a learning problem are seen not only as he does his schoolwork and talks about school, but also as he goes about his daily life. These include:

- Inattentiveness. The child does not seem to pay attention to directions or to what he is supposed to be doing.
- Anger or sadness. When asked to do something, he becomes irritable and may even blow up. He seems to lack interest in things he used to love. He complains about stomach aches on school mornings. He complains about his teachers as unfair or mean or boring. He says he has no friends.
- Impulsiveness. The child often does not use his verbal skills to express himself but just bursts into action, and as a result his performance often suffers.
- Daydreaming. The child often seems to be off in his own world. He is tuned out, preoccupied.
- Restlessness. He fidgets, has a hard time sitting still, and is always dropping things. He often talks too much, almost compulsively.
- Poor self-esteem. The child is full of self-doubt, as if he knows that something is not quite right.

The Parent-Teacher Conference

"If your child exhibits any of the signs listed above, you should ask yourself, "might he be struggling with learning?" And if your child's teacher has not contacted you, you should request a conference. Do not assume that because the teacher has not voiced a concern there is no problem.

What You Should Ask

"There are several questions that you should ask the teacher at this conference. These points may be covered by the teacher's initial comments, but if they are not, ask them one by one. Bring a pad and pencil and write down the answers.

- How does the child's performance on tests compare with his everyday use of certain skills?
- How does his performance in class and on class tests compare with his performance on standardized tests?
- How does the teacher compare/rate the child's connectedness to adults and to other children?
- Is there a noticeable difficulty understanding new concepts?
- Does the child try to avoid certain activities, such as gym or written work or oral reports?
- Is he restless in class? Does he fidget in his seat?
- Does he seem less mature than his classmates?
- Does he seem resigned to failure? Has he given up? Is he an underachiever?

"Answers to these key questions will be very useful, maybe critical, in defining the source of your child's difficulties."

This book was written with the aim of providing parents with the means to discover, discuss, and help their child's learning problem. By describing methods to encourage cooperation between teachers and professionals, *Why Is my Child Having Trouble at School?* can enable parents to build a strong network of advocacy in school and at home to help their child succeed. ■

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Dental care is important for both children and adults with disabilities. Unfortunately, the opportunities for educating dental professionals are limited.

Dental Care for People With Disabilities:

Prospects & Problems

by H. Barry Waldman, DDS, MPH, PhD
and Steven P. Perlman, DDS, MScD

More children are unable to get dental care than any other health service—and that applies to children of all ages, races, and ethnicities. Children in low-income families, families without health insurance, and children in fair or poor health experience the greatest difficulties in securing needed dental services. As bad as this situation is, it only gets worse when these children reach adulthood. Youngsters and adults with mental retardation and developmental disabilities, especially experience frustration as they and their families attempt to locate practitioners willing to provide the needed dental services. Yes, there can be technical, behavioral, and related difficulties in providing dental services for people with profound disabilities. However, equally significant is the limited educational opportunities for care of people with special needs in dental school training programs and the grossly inadequate financial support available to provide the needed care in private practices.

> **In the late 1990s, more than half of the dental schools in the United States and Canada provided less than five hours of classroom instruction in the dental management of people with disabilities.**

Limited experience in dental school

In the late 1990s, more than half of the dental schools in the United States and Canada provided less than five hours of classroom instruction in the dental management of people with disabilities. In almost three-quarters of dental schools, between only 1 and 5 percent of the students' total clinical experience was devoted to treating people with special needs. These findings actually represented an improvement since the early 1990s.

Inadequate financial support

The perception is that dental care is expensive. The reality is that dental costs are "felt" more than other medical costs because almost 50 percent of all spending comes out-of-pocket. By comparison, only 3 percent of hospital and 15 percent of physician costs are not covered by government agencies and insurance companies. In addition:

- Only 4 percent of dental costs are covered by governmental programs, compared to 61 percent of hospital care and 32 percent of physician services.
- Individuals with disabilities have less private dental insurance than the rest of the population, and as result, pay more out-of-pocket for needed care.

Medicaid

Almost 90 percent of government support for dental care is provided by the Medicaid program. By the second half of the 1990s, more than 36 million people were covered by the federal-state partnership arrangement to provide medical assistance for eligible low-income populations. In the twenty year period since the mid 1970s, the number of eligible beneficiaries with disabilities increased by more than 150 percent. Total Medicaid health care payments for more than 6 million people with disabilities reached $52 billion in 1996.

> **In almost three-quarters of dental schools, between only 1 and 5 percent of the students' total clinical experience was devoted to treating people with special needs.**

Understanding Medicaid dentistry

Child dental care is a required component of Medicaid (under the Early and Period Screening, Diagnosis, and Treatment Program). Nevertheless, fewer than one child in five eligible for Medicaid dental services receives pre-

continued on page 28

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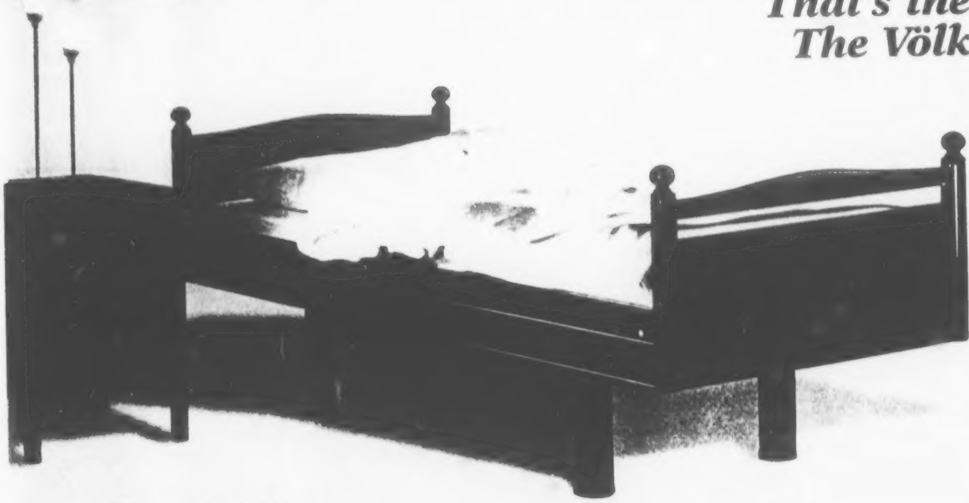

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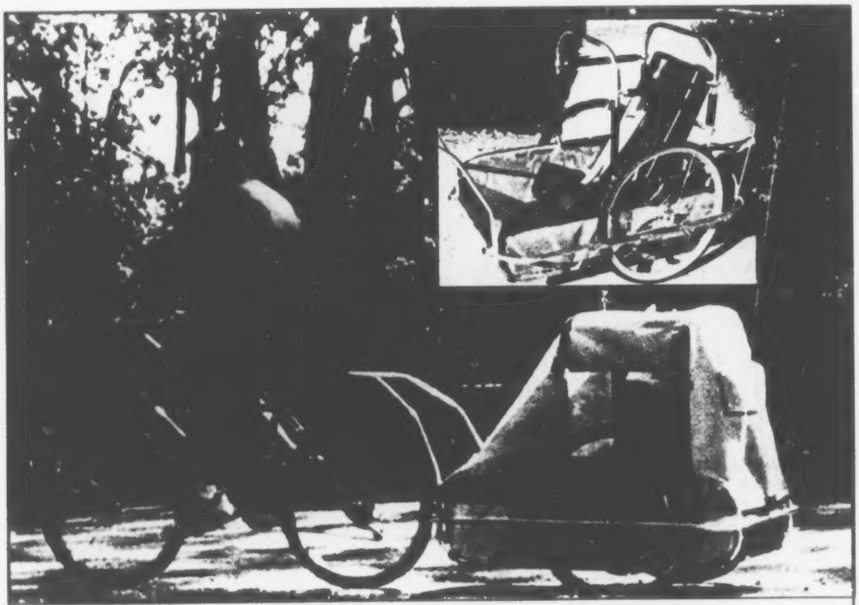
Child dental care is required of Medicaid under the Early and Periodic Screening, Diagnosis, and Treatment Program. However, fewer than one in five children receive preventive dental services



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continued from page 27

ventive dental services, and this percentage is dropping. In addition, dental care is an elective service for adults served by the Medicaid program. In many states, Medicaid offers limited attention to dental care for adults (some states provide only emergency relief of pain and infection). But Medicaid serves as the primary, and at times, the only source of support for dental services for individuals with mental retardation, developmental delay and other disabilities.

Between the mid 1980s and mid 1990s, national Medicaid dental expenses more than doubled. However, this increase just maintained parity with the rate of inflation and did not keep pace with the increase in the number of dental patients. As a result, the national average of $166 spent in 1996 per Medicaid dental patient really was more than a 10 percent reduction from the rates in the mid 1980s.

This level of spending was not uniform throughout the country. Less than $100 per Medicaid dental patient was spent annually in Maine, Maryland, Michigan, and the Virgin Islands, and less than $125 was spent in the District of Columbia, Missouri, Mississippi, Pennsylvania, and Wisconsin.

Understanding dental practice

In the late 1990s, overhead costs in a dental practice (for such items as rent, staff salaries, supplies, infection control, and insurance) were between 60 and 70 percent of usual dental fees. In some states, Medicaid fee payments represented as little as 10 percent of the usual fees paid by private insurance companies. Forget about profit—Medicaid fees never come near the costs of running a dental practice. Two-thirds of dentists in the United States do not accept Medicaid patients.

Charitable dental care

One should not get the idea that dentists are unwilling to assist individuals and families with limited finances that are in need of dental services. In 1997, the American Dental Association reported that almost two-thirds of dental practices provided charitable dental care.

Where are we going? Dental schools are

When fees are raised for mandated child dental services, in some states, adult dental care is is curtailed even further.

recognizing the need to provide their students with the needed educational experiences to provide care for clients with disabilities. State dental societies are initiating lawsuits to force increases in Medicaid fee schedules. Unfortunately, when courts have ruled that fees must be raised for mandated child dental services, in some states adult dental care (the elective component under Medicaid) has been curtailed even further. Spending for adults is sacrificed in an effort to limit total expenditures for dental care.

These limitations in spending come at a time when adult services in our communities are more necessary than ever. Thousands of individuals who have mental retardation/developmental disabilities now live in community group homes and residences. In the past, this population would receive needed dental care from practitioners employed by the state in the large public facilities, but now is dependent upon private dental practitioners for service.

Individuals with disabilities and their

continued on page 30

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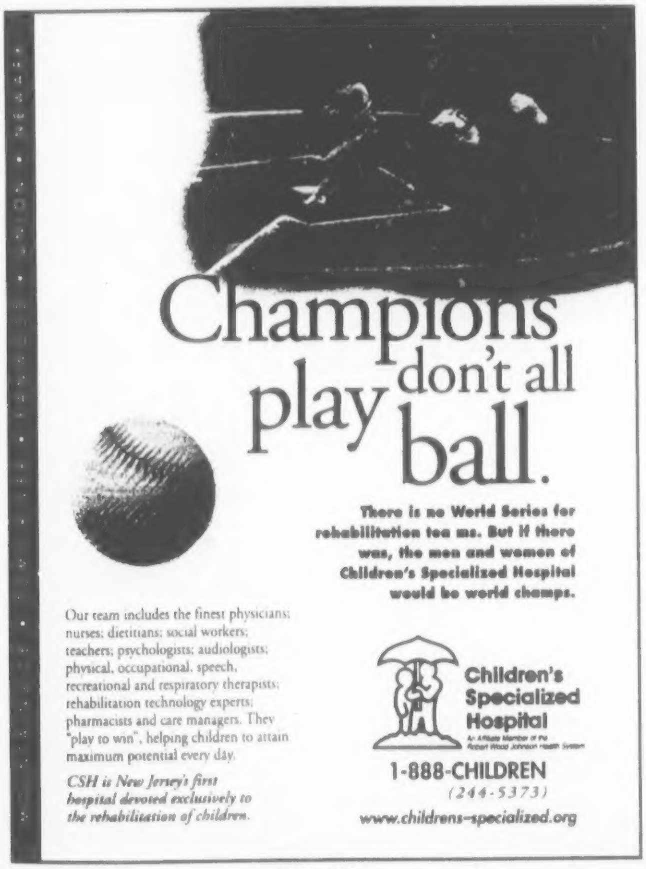

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Circle #24

Together we can ensure the needed dental care for people with disabilities!

continued from page 29

families can help by joining the effort to:

- Maintain pressure on dental schools to improve student abilities in the care of patients with special needs.
- Demand that state governments and insurance companies provide realistic payments for services in the offices of practitioners and, if necessary, in hospital settings.

Together we can ensure the needed dental care for people with disabilities! ■

H. Barry Waldman, DDS, MPH, PhD, is Professor of Dental Health Services at the Department of General Dentistry at the School of Dental Medicine at the State University of New York, Stony Brook, NY.

Steven P. Perlman, DDS, MScD, is the Clinical Director for Special Olympics Special Smiles, and is also Associate Professor of Pediatric Dentistry at the Boston University Goldman School of Dental Medicine.

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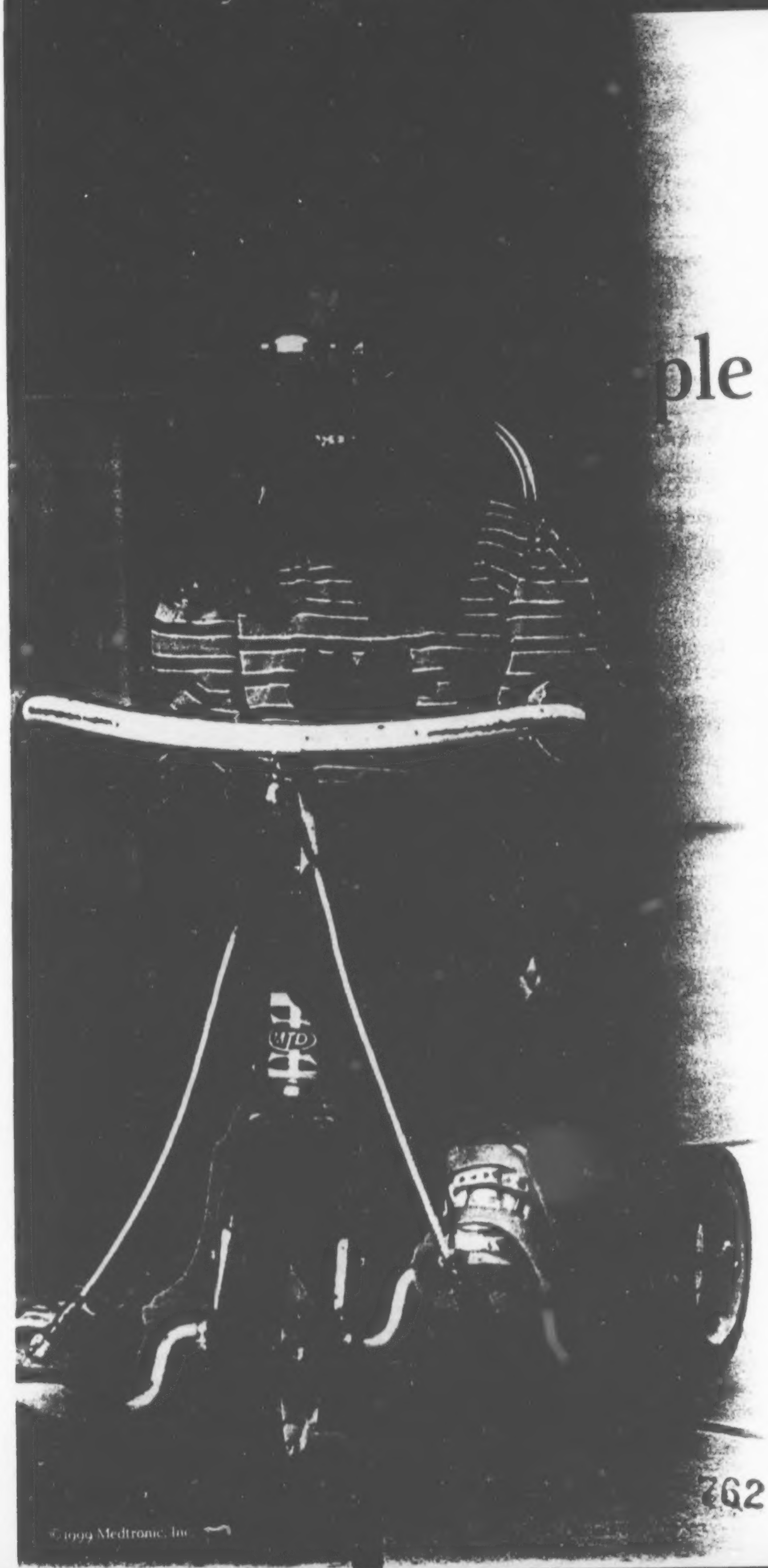
If you or a loved one has cerebral palsy



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AN UNACCEPTABLE RISK

Preventing Sexual Abuse of Special Children

by Jennifer Graham

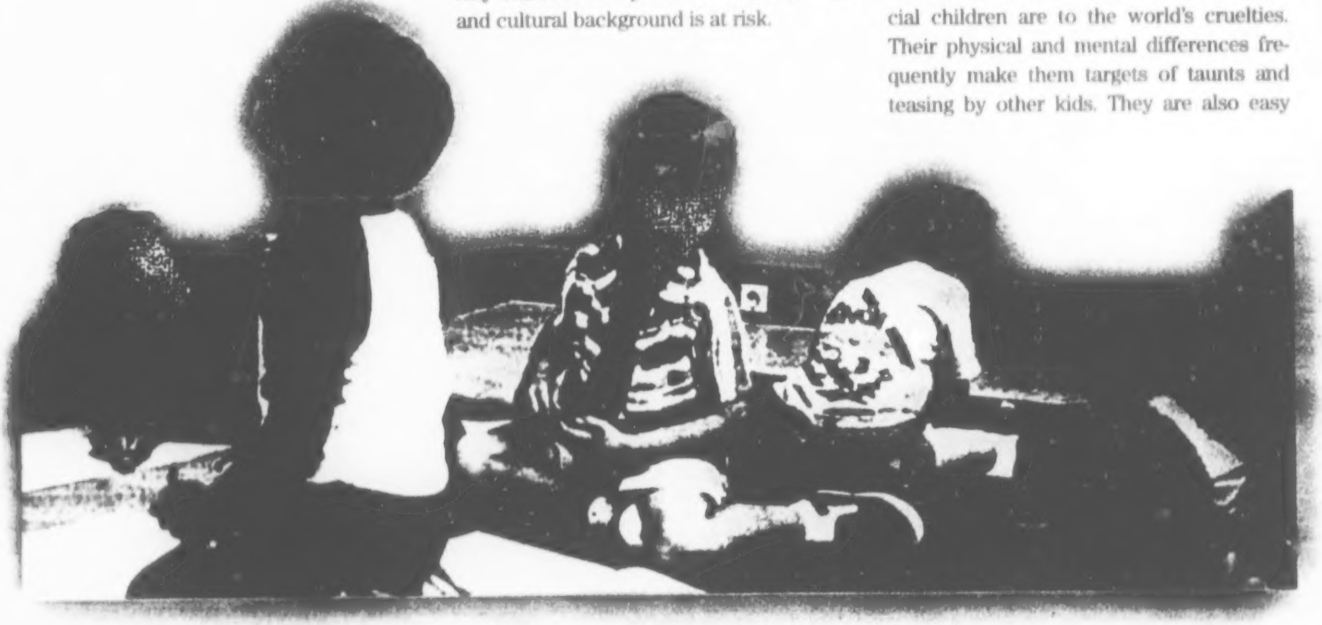
Linda* thought her 4-year-old daughter, Joy*, who has developmental delay, was safe in a trusted relative's home for the weekend. When she returned, however, she found her little girl walking "funny" and pointing between her legs. Thinking she needed to use the bathroom, Linda took Joy to the toilet. As she pulled down her little girl's panties, she could not believe what she saw. Emergency room physicians confirmed Linda's terrifying suspicion: Joy had been raped.

Physical or sexual abuse of a child is one of the most horrific fears of any parent. The statistics are chilling—one in ten boys and one in four girls are victims of sexual abuse before they reach adulthood; three children a day die as a result of physical abuse or neglect, according to the U.S. Department of Health and Human Services. Experts agree that in today's society no child is safe. Any child from any socioeconomic, racial, and cultural background is at risk.

For children with disabilities, the risk of being abused is enormous. Nora Baladerian, PhD, clinical psychologist and director of Disability, Abuse and Personal Rights Project (DAPR) in Culver City, California, a national organization focusing on abuse issues of children and adults with disabilities, believes that children with disabilities are abused at ***seven times*** the abuse rate of other children.

"Kids with disabilities are generally not believed. Their symptoms of abuse are too often attributed to their disability," says Dr. Baladerian.

Parents know how vulnerable their special children are to the world's cruelties. Their physical and mental differences frequently make them targets of taunts and teasing by other kids. They are also easy



* Names have been changed to protect identities

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prey in the bathroom. Many abusers assume that kids with disabilities "won't be able to tell" or "won't know what's happening."

"Harm comes to the most vulnerable," says Linda Mitchell, PhD, CCC-SLP, assistant professor of early childhood special education at Wichita State University and a national expert on abuse and neglect of children with special needs. "We all have to start thinking about the fact that infants, toddlers, people with disabilities, and the elderly are the most highly abused populations. We must empower kids with disabilities through their own voice—whether it be verbal, behavioral, signing, drawing, or communication boards—to tell us what is happening to them."

Places around the U.S. where special kids, verbal or non-verbal, can tell medical or legal professionals about being abused are few. However, both the Counseling Center in West Los Angeles (directed by Dr. Baladerian) and the Child Abuse Referral and Evaluation Clinic (CARE) in Philadelphia have trained medical staff to evaluate children with special needs who are suspected of being abused. At both facilities, the child and his or her family are referred to counseling for healing and education to prevent further harm. The family can also be referred to legal authorities who will assist them in pressing charges against child molesters.

As part of Children's Hospital of Philadelphia, CARE offers medical evaluation and treatment for assessing cases where abuse is suspected. Referrals to other professionals, including psychologists and speech therapists, are made for ongoing treatment. By working with pediatric experts, nonverbal children can communicate what has happened through drawing, sign language, and play therapy.

The first job of the evaluator is to gather as much information about the child as possible from the family, school, and other agencies providing support services. During the medical evaluation, a great deal of attention is given to assessing the developmental and communication level of the child, making sure that the child understands what will happen next in an attempt to make her feel comfortable.

Of the cases of substantiated abuse handled at CARE (of children with and without special needs), most children were sexually molested by someone responsible for their care, someone they know.

During Joy's medical exam, she kept crying out a man's name, saying "Stop! Stop, ___. It hurts." The man was her relative's boyfriend.

"Regardless of a child's level of cognitive functioning, all children are frightened and confused by sexual touch," says Dr. Baladerian. Children need to be empowered to protect themselves from inappropriate or

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"uncomfortable" touching from strangers and, in particular, from people they know. For example, parents of children with disabilities need to help their kids understand that it is not appropriate to hug strangers.

"People take advantage of their affection," notes Angelo Giardino, MD, a CARE staff physician at Children's Hospital of Philadelphia. "Because of their cognitive functioning, it gets confusing to judge situations and they can be easily tricked into situations that are not in their best interest."

Dr. Giardino also advised parents to use appropriate names for the genitals to "demystify" those body parts. "You take away the mystery by talking about it and open the lines of communication. Let your kids talk about their 'private areas' and tell them about the issues of boundaries and privacy. They need to know that it is OK for them to say 'No.' Explain to them why a caregiver can help them with toileting but it's not OK for that person to touch their genitals. Share information."

"Children with special needs typically have many more adults providing them with a variety of services in their daily lives than do other kids," Dr. Giardino continues. "That puts them at greater risk of being in the care of a pedophile. Sadly, in our society, the risk of sexual abuse is everywhere and children must be educated before they enter public school about good touch vs. bad touch."

Parents need to rely on their own intuition and heed the warning signs. They should never be restricted from visiting their child in a school or recreational setting. If a child suddenly becomes withdrawn or aggressive, parents should ask their child if something has happened. The child's doctor should be consulted immediately. Though bruising is often found to be caused by ill-fitting mobility devices or by self-injurious behavior, it can indicate abuse. Both scenarios should be investigated to find the cause.

Linda and Joy are still receiving treatment for the trauma of rape. Joy's therapist believes the little girl will need long-term treatment to cope with her fear and anger. Her mom is trying to work through her feelings of guilt because she was unable to protect her child from a man she knew. And she is also especially vigilant with her other children.

"I try to watch them 24 hours a day and have eyes in the back of my head," she says. "I talk to them about good touch/bad touch and I've told them to bite, kick where it hurts and scratch to get free and run away. I give my kids information so they know what to do."

DAPR Director Dr. Baladerian says every center working with children with disabilities should have multiple information sessions on abuse to instruct the children and the caregivers throughout the year. Children should also be integrated, not isolated in school or recreation. Being included makes them more visible and less vulnerable. Dr. Mitchell warns against always fostering compliant behavior in children with special needs. Teaching children to always do as adults tell them can increase their vulnerability. Dr. Baladerian concurs, saying, "When a child says he does not want any more food, this should be respected. If not, assertion becomes meaningless and is definitely not any help in danger."

Baladerian teaches verbal children and adults to use an individualized response plan as a way to stop a perpetrator. When someone's touch is hurtful or frightening, the child should repeatedly chant like a mantra, "I'm gonna tell my mom. I'm gonna tell my mom."

Teaching children and adults with disabilities physical defense moves if someone is hurting them is another method Baladerian recommends. Both parents and children should pay attention to their intuitive sense of danger. It is, says Baladerian, our greatest self-defense tactic.

For further information contact:

CARE Clinic
Children's Hospital of Philadelphia
(215) 590-4923

Disability Abuse and Personal Rights Project
Culver City, CA
(310) 391-2420

The Arc of the US
National Headquarters Office
(800) 433-5255
(301) 565-3842
(301) 565-5342 (fax)
E-mail: Info@thearc.org
Web site: http://www.TheArc.org
Contact the national Arc for the chapter nearest you. The Arc Web site contains information that can be found by typing in the words "Preventing Sexual Abuse" into their search engine.

Dr. Giardino says kids can heal emotionally from abuse—in time. "We have to give them the opportunity to work through the trauma psychologically, using appropriate methods for their developmental level. Talking, art therapy, and play therapy can all help. They need to vent their emotions and learn to feel safe with new people. Each child will have a different time frame for healing."

The damage done by abuse affects more than the child and his or her parents.

"Everyone who cares for the child is a victim. The grandparents, siblings, extended family, even caregivers or teachers need therapy. Their trust has been taken advantage of."

Experts list these as some of the warning signs of abuse:

- Unusual fear of parents or adults
- Aggressive behavior; acting out
- Withdrawal or a "blank" effect
- Poor self-concept
- Repetition of negative or manipulative behavior to elicit attention
- Unexplained bruises
- Compulsive masturbation or sexualized play
- Nightmares
- Suicide attempts

Children are less likely to be victims of abuse if parents or caregivers:

- Talk to children about abuse just as they would any other safety issue.
- Teach children that their bodies belong to them, and NO ONE has the right to touch them without permission.
- Teach about respect of self and others.
- Teach the concept of good touch (hugs, comforting pats) vs. bad touch (hitting, slapping, hurting) vs. uncomfortable touch (touching in private parts that make a child feel uncomfortable).
- Explain the concept of good secrets vs. bad secrets.
- Encourage children to always discuss concerns with a parent or trusted adult. ■

Jennifer Graham is the mother of two daughters, one of whom has Down syndrome. She is also a freelance writer and lives in Pennsylvania.

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Passing the Test

Special thanks to Missy Long (pictured below, far left), independent living counselor at Ramapo College, who availed EP with this congenial group of students for interviews.

College Students with Disabilities Talk About Making Successful Transitions to Life on Campus

by Gale Jurasek and David Chamalian

EP had the privilege and pleasure of speaking with a group of students with disabilities who are matriculating (or graduated this spring) at Ramapo College in Mahwah, New Jersey. All of the students are in their early twenties, and they spoke on a variety of subjects. Although they focused on different issues, the message behind their words was the same: We are succeeding!

Beatrice Olivetti—"Real World U"

Beatrice, who has been blind since birth, is a junior majoring in Business. She found that, in one respect, making the transition from high school to college was not too difficult. But, she hastens to add, that does not mean it was easy. As a child, Beatrice recalls, she was coddled in school. In college, however, she notes, students, even those with disabilities, receive far less individual attention. "College is a sink or swim environment. Either you perform well and get your work done, or you fail."

The college experience, she adds, requires perseverance and self-motivation. "Taking on the little tasks and just doing them, hands-on, was how I learned to be independent. My roommate was a big help to me, but I learned things either by doing them or asking someone to show me. College is good real-world preparation."

Beatrice describes herself as a religious person and said that God would not give her a test that she would not be able to handle. Likewise, she refuses to let her blindness impede her enjoyment of the things she loves: working on the computer (with a screen reading program), reading, listening to music, shopping, hanging out with friends, and renting videos. She also knows how to take the good with the bad. "I'm not Miss Mary Sunshine everyday, but I look at the bright side of things. I have a loving family and friends and a wonderful roommate."

Beatrice has a support network of friends whom she can rely on, and has found it helpful to set goals, be a good time manager, and maintain a structured lifestyle. "But," she says emphatically, "I always try to let a little spontaneity in my life."

Tiffany Jessen—No sophomore "jinx"

Tiffany, who just finished her sophomore year, has been legally blind since age 11. She is diagnosed with atypical bilateral Coats disease, a rare, hereditary syndrome characterized by the enlargement of the ends of the blood vessels in the retina. Though it most often affects only one eye, and is more common in males than in females, Tiffany, now 20, has the rare disease in both eyes.

Tiffany went through a period of several years during which she lost her sight, regained it, and lost it again. She started using a cane when she was in her early teens, and later went to a school for individuals with a visual impairment.

The transition to college was at first a big challenge for Tiffany. She soon learned that she was not going to be treated differently. It was the people whom she met, however, who made the adjustment smoother. "I had a great roommate who, along with her friends, was very accepting."

Building confidence and being willing to meet new people are anxieties that all people experience, according to Tiffany, even those without disabilities. "Having a roommate who wouldn't accept me concerned me in the beginning. All new freshman have that problem." However, reflecting on the pleasant experience of living with her last roommate, Tiffany says that meeting the right people is one of the keys to successful college life. "If an incoming freshman asked me, I would say take the risk and keep searching for a roommate you like. Living alone is lonely. Being around people is a lot more fun."

Tiffany will be attending seeing-eye dog training in July to help improve her speed and confidence in getting around. She confesses that though she misses the activities she loves, like biking and jogging, she does not want anything to keep her from being active. "My independence is pretty much unhindered by my blindness." Nevertheless, Tiffany says that the major hurdle to her greater independence is the inadequacy of the public transportation system in her area, even for nondisabled people. "There are simply not enough trains or buses available for those who rely on them."

Tiffany does not let blindness define her. She continues to makes her mark as a nationally ranked goalball player and future Paralympic hopeful. "I consider myself a person, not a blind person."

EDITOR'S NOTE: Goalball is a sport played on an indoor court using a large, heavy ball with bells inside. The ball must be rolled on the floor to be in play. Players cannot see the ball and must rely on all their other senses.

Going to college signifies the beginning of a new stage in the lives of all young adults. With it comes growing independence and participation in the world. These years are often the final stage of "growing up," and can be extremely rewarding—and challenging. For young adults with a disability the challenges are great, but so are the rewards that await them.

Developing independence from the family is the critical issue in the transition to college. Making new friends, succeeding in a new environment, and last but not least, managing all the academic demands

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Jen Murray—The old college try

Jen, who has spina bifida, is a senior majoring in Journalism. She has been using a wheelchair since she started college in 1995. Jen felt it was a good choice simply because it is easier to get around campus, especially over long distances. "I definitely have more mobility in a wheelchair, but it is hard to get up hills without my friends' help." Her advice about independence and mobility is straightforward and practical and seems to be the mantra with which she lives her life. "I try, but if I can't do it, I can't do it."

Jen knows how much she can do physically and adjusts her choice of mobility devices accordingly. When not in her wheelchair, she prefers to use braces and crutches. She enjoys the versatility and comfort of being able to change positions. Regardless, she lets nothing prevent her from getting around and enjoying activities with friends. "I don't drive but I go out with my friends, and they'll drive me. My parents drive me places too." When traveling, she brings her collapsible wheelchair, which can come apart in three different places if it has to, so she never has to worry about lack of mobility at her destination. "I'm pretty mobile," she says.

A writer at heart, Jen feels comfortable with herself and with college life. She maintains a positive outlook on life in general. "I do the best I can with whatever comes along."

Danny Roldan—A student of life

Danny, a senior Sociology major who has cerebral palsy, has always been pleased with the mobility and independence his comfortable crutches, which he has used all his life, have afforded him. He could not, however, always take his mobility for granted. After an accident in school, officials required that he begin using a walker. Danny, "not being a walker person," and his mother then fought a months-long battle with his school system's Board of Education to win back Danny's right to use his crutches again. "Sometimes, for people with a disability, it's a struggle getting what you want." For Danny, frustration is often built on other people's ignorance. "When people don't know you, they think you can't do most things. But I was raised to have an independent attitude. I wanted my crutches back. And as hard as it was, we just kept on fighting."

From the time he was very young, Danny's parents taught him to do things for himself. "My parents showed me how to get dressed, brush my teeth, things like that, by myself." That he had learned to care for himself gave him the confidence to move 100 miles away (Danny's home is in southern New Jersey, and Ramapo College lies at the northern tip of the state) and brave his new surroundings alone, without knowing anyone. "I was not afraid of going to college because I knew it would be different." Nevertheless, like anyone else would be, Danny was preoccupied about fitting in. "As a kid I was independent but not very social. I would come home from school and basically do nothing. At college, I knew I had to be social in order to grow. I realized that it was important to be outgoing and make as many friends as possible." According to Danny, meeting people and acquiring social skills in grade school is an essential ingredient in making the transition to college less stressful.

Danny, who enjoys sports such as soccer and basketball, and dreams of one day seeing an L.A. Raiders football game, has made a lot of friends at school, but still enjoys finding his own way. "I get around campus on my own, I go to New York City [a one-hour commute from his home], I walk around my town, go to the bank." He also feels pleased when people offer to help him, even when they just hold a door open for him. He claims that they admire him and offer their help sincerely. "People are always willing to help and make it easier. Just the fact that they want to help makes a difference." Danny does not leave the house without his no-looking-back approach: "Life is as you want it to be. I don't look at anybody else and say, 'I could be like that.' I could be worse, I can't complain. You take what you have."

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involved, such as getting around campus and especially to classes, make up a large part of the challenge and can trigger anxiety. The group of students with whom EP spoke relate that the challenges they faced were mainly the same as those faced by all college students, regardless of ability. They pointed out that in the post-secondary setting, there is much less structure and more independence. It is up to the student to motivate him or herself to succeed.

Thank you, Ramapo College, for allowing us to speak with these five individuals, who have a lot to teach people, with or without disabilities, about overcoming the challenges of transition into a new stage of life. These students have faced and overcome challenges and have emerged strong and self confident. Anyone can benefit by reflecting on the experiences and advice of this group.

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Kim Salzmann—**Driven to succeed**

Kim graduated last month with a degree in Mathematics and considers herself fortunate in many ways. Diagnosed with spastic diplegic cerebral palsy at age 2 and later with athetoid overtone (involuntary movements), she looks forward to reaping the rewards of her education and continuing to do the things she has always enjoyed, such as skiing, swimming, and now, driving a car.

Sold to her by a regular dealer, Kim's car has been modified with a removable attachment to the steering wheel called a tri-pin (see photo). This device gives Kim total control during steering while relieving her of the normal hand-over-hand motion that she cannot do. Says Kim, "Just recently I started to drive, whereas most people start a lot younger. That frustrated me because I had always been pretty independent. Now I feel 'normal' because the car gives me that independence and makes me feel just like anyone else." Kim uses her car about four times per week to run errands, go the movies, and do other activities. "I no longer have to call people up and ask them to take me places."

For Kim, college was scary at first. There was a sense of trepidation, she recalls, upon seeing how other students reacted to her. She soon realized that the more friends she made the better off she was. The new-student orientation meeting held at the beginning of her first semester was the foundation on which she built many of her campus friendships. "The OSS (Office for Special Services) had an activity for all new freshman and transfer students. At that meeting, I made a lot of friends, many of them people with disabilities. But through those friends I eventually made connections with other people, non-disabled people."

One of Kim's constant frustrations is conveying to other people that her disability is only physical, not mental. "When people hear me speak, they assume I have mental retardation." Overcoming this hurdle was essential, she says, but not difficult when other people have been given the chance know what kind of person she is. Her advice to anyone entering college is to "get involved in clubs, work on your independence so you don't learn to to take your friends' help for granted," and most important, "just be yourself and like who you are. If you do, other people will like you, too." ■

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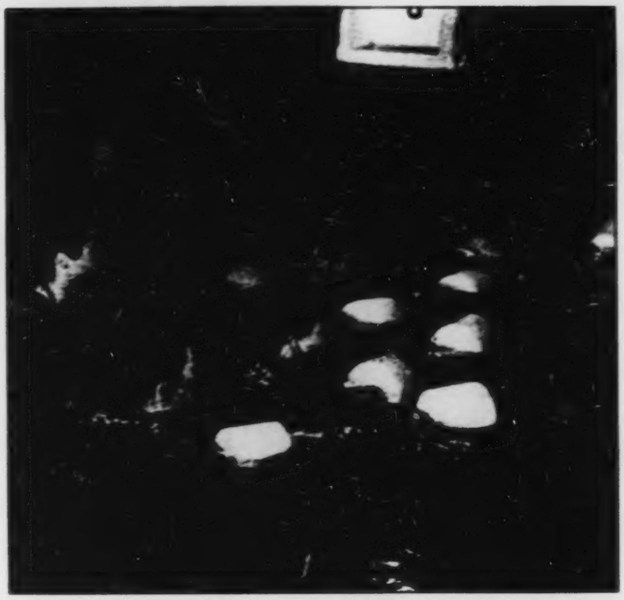
EVERYBODY IN THE POOL!

"Teen Team" adapted aquatics program gets young people with disabilities into the swim of things!

by Paula Wanzer



Together teens deal with floating lane lines, one of the many obstacles they must navigate in participating with Teen Team.

Teens with disabilities are churning with untapped energy. They revel in an environment that challenges and builds their abilities. Through the Teen Team, the newest addition to the Dover Adapted Aquatics Program, adolescents with disabilities channel some of that energy into team sport—building self-esteem, having fun, and socializing along the way!

Sponsored by the Recreation Department of Dover, New Hampshire, the program emphasizes creative problem solving, fitness, and aquatic skill mastery. As each teen engages in these activities, she challenges herself to work as a team member with other class members and volunteers.

Why water?

The Dover Indoor Pool, the public recreation facility where the Program is held, reverberates with a happy clamor when the teens descend upon it. Besides the benefits that are arise when young people get together in such a setting, the water itself is naturally therapeutic. Its buoyancy allows a teen with a disability to maneuver in ways that would be difficult for him on land. While the buoyancy reduces stress on his joints, water provides resistance. This resistance requires him to work harder and increase his strength. There is also the "turbulence factor." The more turbulence, the harder he works. With a pool full of active teens and volunteers, there is an abundance of turbulence!

Another advantage to taking the plunge into water is the opportunity for developing swimming and water safety skills. Swimming is a "closed" skill, meaning it is repetitive and does not require quick changes in strategy. This makes it relatively easy to learn. The challenge of the aquatics program is allowing the participants to use and improve upon their skill. These combined factors present teens with an activity that promotes fitness and collaboration, and is an excellent lifelong leisure skill.

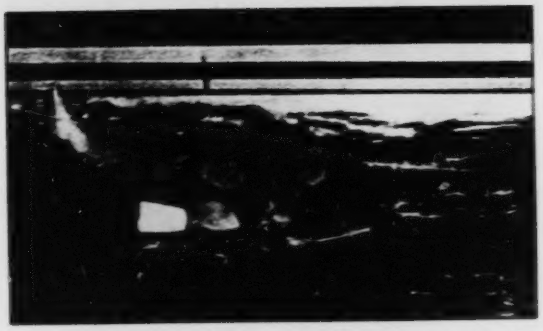
Getting started

Parents in the Dover area who have teens with disabilities knew they wanted recreational activities that would meet the needs of their children. They let the Developmental Services of Strafford County (their area agency that provides information and services to individuals with developmental disabilities) know about their concerns. The Dover Pool already had an adaptive aquatics program coordinated by One Step Further, a small business that specializes in leisure education programs for individuals with disabilities. Putting the pieces together, the organization rose to the occasion. In collaboration with Developmental Services and the parents, One Step Further and the Dover Pool came up with Teen Team.

Setting the plan into action

On Teen Team, we ensure that each teen understands that he or she is an integral member of the group. With that knowledge, teens are better able to master skills while having fun with peers. We help them increase their fitness level, solve aquatic challenges, cooperate with others, and assume leadership responsibility. For teens, this kind of success will open the door to gaining a host of other skills, such as increasing their ability to socialize, gaining vocational skills, and being included in other community leisure activities.

We recruit and train volunteers from the community and from the University of New Hampshire. Volunteers are thoroughly trained by certified water instructors. In addition to taking a three-hour course on water safety, CPR and First Aid, volunteers are trained to work with young people in this setting and in the framework of the program. Each volunteer donates his or her unique style and perspective to the program. They burst with ideas and energy for making the program even more exciting.



Teen Team participants are paired with peers or volunteers in the quest to reach for their objective.

Different strokes

To create the challenging environment, we use inner tubes, aerobic aqua steps, fun noodles, lane lines, and foam bar bells. We purchased boat "bumpers" (floating cushions used to protect the hulls of boats from bumping the dock) and rope from a marina, as well as folding gym mats from a sports catalog. Although gym mats are expensive, they are worth every penny. Inner tubes and mats put swimmers and non-swimmers on the same level with each other. For instance, non-swimmers and swimmers lay on the mat and flutter-kick together. When two teen members hang on and kick the inner tube across the pool, it does not matter whether they both can swim; the tube supports them both. When participants feel safe and supported with equipment and each other, they work together to solve problems and reach a goal.

Just doing it

Although the program appears disorganized, there is a definite structure. Everyone is actively involved at their own level. This structure allows for support to be tailored to the individual, no matter what his or her ability. With this support, he or she effectively builds skills for mastering the environment. We do this by using what we call a "frame." There are three stages within our frame, an opening, middle, and closing. The frame, as a whole, serves to help participants organize themselves and prepare for different mental and physical challenges. The challenges include: following directions, absorbing new information and flowing from one activity to another.

OPENING

We open in the shallow area, and each teen is paired with a peer or volunteer. This permits non-swimmers and swimmers to par-

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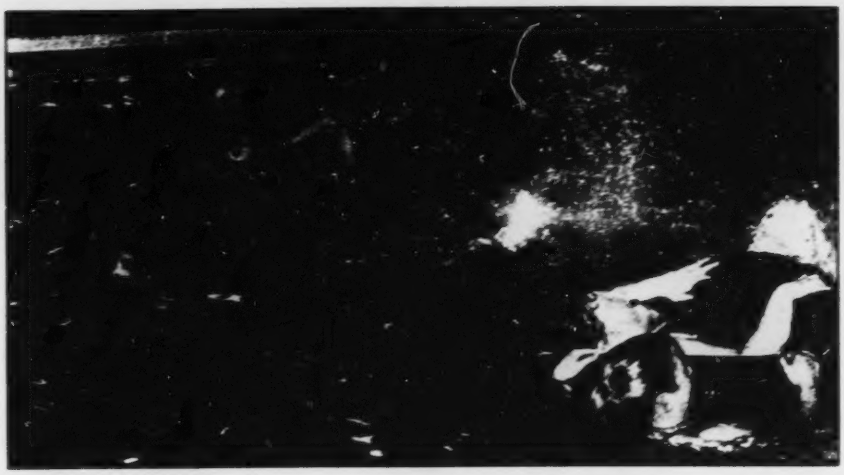

Hanging onto inner tubes, the team partners thrash their way across the pool. The turbulence they create intensifies the challenge—and the fun!

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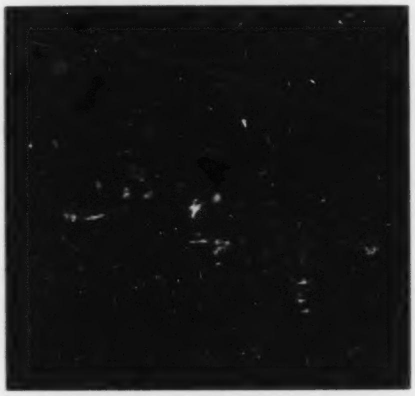
ticipate safely. Some participants wear aqua belts, which help them float. To begin, we create a circle and engage in a warm up routine. For our warm up, we start with one person raising her hands above her head and putting them down, and we go around the circle with each participant doing another, similar exercise. This ritual organizes our energy, focuses our attention, and prepares us for strenuous physical activity.

MIDDLE

The middle, both mentally and physically rigorous, provides both our brain and muscles a workout. For instance, we maneuver through the water, over, under, and around obstacles to a 'floating island' (mat). Next, weighted aerobic steps are laid across the bottom of the pool so that we find our way to the end of the pool by bobbing and bouncing from aerobic step to aerobic step. Some team members receive support and alternative challenges.

The action then moves on to the diving well area, where everyone is partnered up. Some teens partner with each other while others want or need the support of a volunteer. Grabbing an inner tube, we jump in and swim across the pool kicking our legs while on our stomach. We return to the starting point and jump in with the tube kicking across the pool on our backs. Upon reaching the end a second time, we grab the lane line and pull ourselves back to our point of entry. When everyone has accomplished this task, we jump in, hold onto a gym mat and move the "barge" through the choppy waters.



Team members partner to get across the pool.

Some students do not have the mobility or the desire to brave the challenges. These students choose to work in the shallow area with a volunteer. They accomplish similar activities but at a slower pace, building confidence and increasing their skill level in calmer waters.

CLOSING

At the end of class, we all gather in the shallow area. After a vigorous workout, students close with a ritual that reunites the group. We form a circle, and while pumping aqua bar bells under water, we chant, "One, two, three, and four!" We then end with a big round of "thank you's" before we all go on our way.

Skills for a lifetime

It will not be long before the teens can use the skills they gain through the program. We visualize that they will eventually be able to: conduct the program themselves, with the staff as facilitators; introduce new members to the program and train volunteers; become adapted aquatic volunteers for the children's program; and learn to access other activities available in their communities.

Working with the community recreation department, parents can be a major force in creating dynamic programs that challenge their teens like Teen Team. Besides the benefits outlined here, the results of recent studies demonstrate that an activity such as swimming has a profound impact on brain growth and development. Whether it be aquatics, dance, sport or art, it can impact the quality of a young person's life forever. ■

Paula Wanzer, MA, CTRS, is a certified therapeutic recreation specialist. As an individual who has cerebral palsy, she understands both personally and professionally the power of movement and play. She welcomes questions and comments.

For more information on Teen Team Aquatics contact:

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Circle #26

Reward Systems Made Simple

One parent describes easy steps for managing behavior problems in a child with special needs

by Susan Senator

As parents of challenging children, we are all confronted with difficult behavior now and then. At some point or another many of us are advised to use behavior-management techniques when parenting our children. And many find, unfortunately, that the technical language, charts, and jargon used by well-intentioned behaviorists are overwhelming and sometimes incomprehensible. Anybody who has sat down to plot the frequency, duration, antecedent and consequence of a maladaptive behavior knows the feeling of frustration that often accompanies behavior-management training. However, one need not give up. It is possible to navigate the sea of behavior-management confusion by picking and choosing a couple of techniques that are straightforward, easy, and fairly successful. I say "fairly" because the truth of behaviorism (and many methodologies in general) is that none of them works forever. Parents and educators must constantly rethink, adapt, and move on. But given that limitation, one can still use certain aspects of behavior reward systems for a reasonable period of time, with a good result. Parents can adapt behavior-management techniques in a personal, if imperfect, way that works for their family. The key is to figure out your family's unique take on it.

The two types of behavior-management techniques I have found useful are token systems and picture charts. Token systems are the way you reward good behavior through the earning of symbolic representation of the motivator. In English this means your child has opportunities throughout the day to earn some designated item (a coin, a marble, or a puzzle piece, as I use with my son Nat, who has autism). After he has acquired a certain number of them, he can have his reward. With each token earned, he is praised for following the rules, achieving a part of his daily goal, and the positive behavior has been reinforced.

Picture charts are visual reminders of the desired behaviors. You can also use images of the negative behaviors that you wish to discourage, which is what I chose to use. Throughout the day, the child is brought over to his picture chart, where he must go over the goals, the desired behaviors, or behaviors he must not exhibit. The images, words, and repetition of visiting the chart help reinforce your message. Once you have an idea of what you need to work on, you are ready to begin.

Determine five goals

The parent decides on around five goals to work towards. In my son's case, I want to stop him from ripping, spilling, hitting, screaming, and breaking people's things (particularly his brother's). Those are not the only things he needs to work on; they are only the most troublesome of his behaviors.

Construct your chart

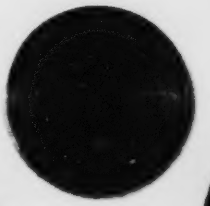
Find images that illustrate the behaviors. Parents can take instant photos of their child, either caught in the act of a bad behavior, or the preferred behavior. You may even cut images out of magazines that fit the situation or draw pictures. Keep the images simple so that your point does not get lost. Once you have your images, print or cut them out and glue them on a long sheet of construction paper (long enough to fit each behavior image). Label the image. Next to the image of the negative behavior I write a large "NO," so our expectation is very clear.

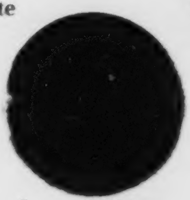
Inform everyone of your intent

Make copies of your chart for teachers, therapists, and everyone who works with your child. Let them know what you are doing and what you would like them to do. Ask them to let you know what happened during the day so that you can keep track of how your child is doing with this system.

Keep track of your progress—but do not drive yourself crazy

Hang a piece of paper next to the image chart and use it to record progress. Write the date and leave a little space for any notes you may wish to make. You may want to make check marks for the number of incidents per behavior per day. Or you may want to simply make a check if it was a relatively good day or not. Do not





obsess over your data collection. It is only a way to keep track, a reminder of what you already know. Too many people give up on the truly useful behavioral techniques because they cannot bear the record-keeping. Do not worry about it. After all, what really counts is how things feel to your family, not whether a graph tells you that you have succeeded.

Use tokens

Token systems go hand-in-hand with behavior charts, further reinforcing the message you want to send. To begin, you must determine what is a true motivator for your child. Consider hobbies, things he talks about, things he likes on TV, and of course, food. Most children can be motivated by something. Sometimes a parent has to be pretty creative to find just what that may be. It may even be something not considered "socially appropriate," but something you can allow your child to do in limited, monitored circumstances. For example, my son's motivator at times is to be allowed to "silly talk." This is often bizarre "self-talk" that some people with autism indulge in. I believe that it is alright for my son to silly talk in private and as a reward. It is something he feels the need to do, and though it is not too appropriate, I feel it is better that he be aware of himself and his need to use silly talk, and to distinguish it from how he talks to others, than to try to squelch it entirely.

Anything that feels like a treat to your child is something to use. The motivator, however, should not be too large a snack, or too expensive or time-consuming. It should be big enough that he looks forward to it all day, like a handful of small candies or one TV show (you must make sure there is enough time set aside for this and that the TV goes off right after). It should not be so big that it overwhelms or is too hard for you to repeat, like a whole movie or an ice cream sundae. Ultimately, you as the parent will know best what to use.

The reward should not be something he gets easily (for example, using a usual daily snack as a reward). Whatever you choose, it must be given to him in the one instance of

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Circle #19

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reward at the end of the day, or whatever period you have chosen, and at no other time. This makes it more meaningful to him.

Find the best unit of time per token

Determine how you want to divide up your day (or hours or week). Figure out what is reasonable for you to accomplish. If your child needs a lot of monitoring, you will need to divide your time up more than if he is working on more long-term goals. If you need to reward him every hour, then you will have to keep track of that many tokens. In my son's case, I divide the day into four units: morning, school day, after school, and night. I suggest as few tokens as you can get away with, while still making a profound impression on your child.

Create a token puzzle

Currently my son's motivator is a popular brand of chocolate and peanut butter candy. I have the wrapper of one of them cut into four pieces, with magnets on the back, stuck on my refrigerator. He adds the pieces to the puzzle throughout the day. If he does well in the morning, he gets the first piece. If the reports from school are good, he gets the second piece. After the tutoring session at home, he gets the third piece. And after doing all of his nighttime routines he gets the fourth piece, completes the puzzle, and gets a single candy. He sees the token puzzle come together throughout the day without actually getting the candy. When he finally gets the candy, he is crazy for it and really enjoys it!

Punishment can affect morale in the family, too. Use the opportunity of a negative behavior to learn what to do in the future.

He always gets to earn back the token

I use the candy to motivate only. I do not punish by removing tokens. If bad behaviors occur, you can bring the child over to his chart and show him what is desirable. Show him the tokens to remind him visually of what he is striving for. Tell him, "The rule is, we do not rip things. Now you have to try to earn your token, because you have not earned it yet." If possible, have your child repair what is damaged and apologize. Or if that only stimulates him to worse behavior, then, as calmly as possible, redirect him to a constructive, contained activity—something calming.

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Circle 178

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Teach him what all people must learn: that he has to find appropriate outlets for his impulses. To say "You just lost that token, Buster. No candy for you!" may feel good in the moment, but you end up losing the opportunity for highly motivated effort. Your child figures that he does not get anything for the rest of the day, so why should he bother being good now? Punishment can affect morale in the family, too. Use the opportunity of a negative behavior to learn what to do in the future.

> **By setting up simple charts and a very basic, direct token system, you can organize your home life in a very dramatic way that will make all the difference to your child.**

Do not worry about the phase out

Behaviorists put a lot of stock in phasing out the reward. This can get very tricky, because if you phase out too soon, your child may lose his motivation. I have found that the motivator itself begins to wear thin over time. Your child will get saturated after a while, and you will know when that happens. At that moment, it will be time to let the reward system fade away and you can either go without the motivator or find a new one, if necessary.

We all know that our children can benefit from structure and consistency, from clear rules and the judicious use of praise. But too often parents shy away from setting up structures and systems in their homes because they are too complicated to use. What works in a classroom may not fit the more fluid, relaxed atmosphere of the home, which is usually bustling with many other distractions. By setting up simple charts and a very basic, direct token system, you can organize your home life in a very dramatic way that will make all the difference to your child. We simply need to remember that it is okay to adapt and bend the techniques we hear about from the experts so that we can construct systems that work for us and our own particular families. Do not be burdened by precision and jargon if it is going to keep you from doing anything at all. Keep it simple and you will succeed. ■

Susan Senator is a contributing editor for EP. She and her husband, Ned Batchelder, and their sons, Nat, Max, and Ben, make their home in Massachusetts.

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Circle #27

The Road To Atlanta

NOVEMBER 10-12, 2000 • WORLD CONGRESS & EXPOSITION ON DISABILITIES

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Host City for First WCD Is Top-Rated for Accessibility

Atlanta was selected as the site of the first World Congress & Exposition on Disabilities (WCD) largely because of the city's praiseworthy accessibility for people with disabilities. The Georgia International Convention Center, where this precedent-setting event will be held November 10-12, is particularly suited to accommodate those with mobility difficulties, as it is all on one level. In addition, the city's transportation system, MARTA, offers one of the most complete transit services for people with disabilities, and many other facilities throughout the region have been designed to comply with Americans with Disabilities Act (ADA) regulations.

An "Atlanta Accessibility Guide" has been prepared by the Shepherd Center of Atlanta and the American Society of Interior Designers (ASID)–Georgia Chapter. The Shepherd Center, a WCD sponsor, is a specialty hospital in Atlanta for spinal cord injury, brain injury, multiple sclerosis and post polio treatment.

The comprehensive guide includes information on a wide variety of services, including many disability-specific resources. It also provides accessibility details on sites such as hotels and restaurants, museums, places of worship, shopping centers and supermarkets, sports venues, parks and theaters. The Guide is available online at www.shepherd.org/dis-res/guide/index/htm, or call: 404-352-2020.

The online version of the Guide includes a link to the MARTA Website where information can be found on the system's Commitment Buses. Equipped with wheelchair lifts and available on most of the 150 routes MARTA operates each weekday, the buses are equipped with wheelchair tie-downs and priority seating for persons with disabilities. As for MARTA's train service, every rail station is 100 percent accessible with special, wide faregates for persons with disabilities. Escalators and elevators are located between the rail, bus and street levels at each station, and each train has a special wheelchair space at one end of each rail car.

For those who are visually impaired, MARTA's rail stations have raised, tactile strips along all rail boarding areas to alert riders where to stand safely while waiting for a train. Station signs have raised and Braille lettering, as do many bus stop signs. For those persons who are hearing impaired, MARTA has a TDD Schedule Information number, (404) 848-5665 which operates between 6 a.m. and 10 p.m. Monday through Friday and from 8 a.m. to 4 p.m. on weekends and holidays.

Atlanta's transportation system (and, indeed, much of the city's facilities) won international praise for the successful way athletes and spectators were accommodated during the Olympic and Paralympic Games in 1996. Since then, the situation has improved even more, as attendees to the first World Congress & Exposition on Disabilities this fall will be able to attest.

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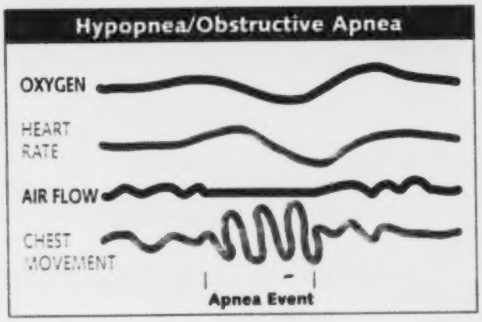
Causes and treatments

by Frank P. Manginello, MD, FAAP, and Mary T. Carbone, MD, FAAP

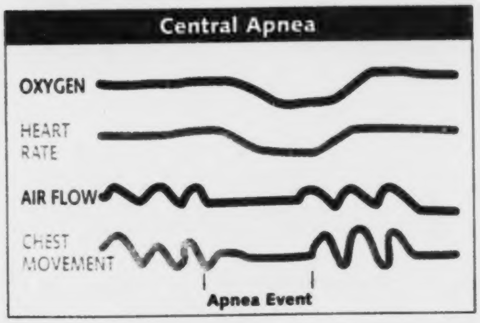


Hypopnea/Obstructive Apnea

Problems with breathing during sleep might be the culprit behind many difficulties experienced by children with special needs. From causing behavior problems and failure to thrive to high blood pressure, sleep-disordered breathing can turn bedtime into "dreadtime" for some children. Sleep-disordered breathing is an abnormality in respiratory patterns and/or gas exchange (the intake of oxygen and expulsion of the waste product, carbon dioxide) experienced during sleep. It is a common problem in children with various types of chromosomal and neuromuscular disabilities and in children with craniofacial malformations. Specific diagnosis of the underlying disability is important, since treatments are tailored to each individual problem. All forms of breathing problems may occur, and in some children, multiple types will also be present.

There are four major types of sleep-disordered breathing:

1. Central Apnea – The cessation of respiratory activity characterized by no chest wall movement.



Central Apnea

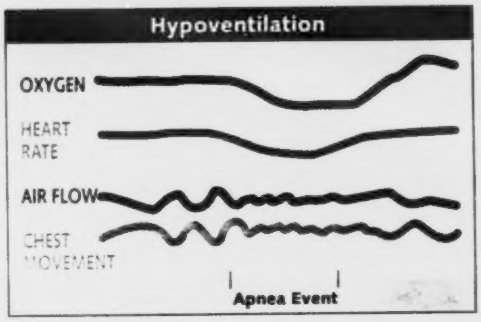
2. Hypopnea/Obstructive Apnea – Breathing associated with partial or complete obstruction at some point in the airway. This can be caused by structural or functional obstruction, muscular hypotonia (low muscle tone), or other neurological conditions.

3. Hypoventilation – A persistent shallow breathing that generally results in hypoxia (decreased oxygen) and hypercarbia (increased carbon dioxide). This is generally nocturnal, but can occur during the day as well, especially in younger infants.

4. Mixed Apnea – Any combination of the above events in the same child.

Some of the most common childhood disabilities and their associated sleep-disordered breathing patterns:

SPINA BIFIDA/MYELOMENINGOCELE (PROTRUSION OF SPINAL CORD AND MEMBRANES)/NEURAL TUBE DEFECT
Though there are a limited number of studies that have looked at breathing abnormalities in children with spina bifida, it has been found that serious sleep-disordered breathing may occur in up to 20 percent of these children. The incidence may vary depending on the severity of the spina bifida, as well as any other associated abnormalities. One example of an abnormality associated with spina bifida is Chiari malformation, in which the brain stem grows into the spinal canal. It is an important cause of sleep-disordered breathing in children with spina bifida because this area controls vital respiratory functions. Episodes of central apnea, obstructive apnea with hypopnea, as well as disturbances in the sleep/wake cycle, are most common. Lack of oxygen in the blood (cyanosis) is also seen among children with Chiari malformation.



Hypoventilation

In other children with spina bifida, obstructive sleep apnea can arise from overgrowth (hypertrophy) of the adenoids and/or tonsils. Snoring is a signal that this hypertrophy is present. With abnormal gas exchange resulting in hypoxia and hypercarbia, the consequences can potentially be quite severe. Three such consequences

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Ask the Doctor addresses issues of concern to our readers and is usually coordinated on a monthly basis by David Hirsch, M.D., a pediatrician and member of Exceptional Parent's Editorial Advisory Board. Dr. Hirsch is a partner in Phoenix Pediatrics, Ltd., in Phoenix, Arizona, and specializes in treating children who have developmental disabilities and chronic illnesses.

Parents should review any suggestions made in this column with the appropriate professionals. Mention of specific products or medications illustrate suggestions and are not endorsements of any specific products.

Send questions to: Ask the Doctor, Exceptional Parent, 555 Kinderkamack Road, Oradell, NJ 07649-1517, or fax, (201) 634-6570.

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have been reported: elevated blood pressure in the blood vessels of the lungs (pulmonary hypertension) due to the longstanding hypoxia, frequent awakenings, and the inability to awaken to appropriate stimuli during sleep. In addition, frequent nocturnal awakening can also lead to behavioral problems as a result of daytime sleepiness, and can accentuate developmental delays.

CRANIOFACIAL MALFORMATIONS

Children with craniofacial malformations are most prone to obstructive events. Disorders such as Down syndrome, Pierre Robin syndrome (a disorder characterized by abnormally small jaw, displaced tongue, and cleft palate), choanal atresia (absence of the opening from the nasal passage to the windpipe), and others, can cause associated sleep-disordered breathing. In children who have syndromes involving severe low muscle tone (hypotonia), collapse of the oropharyngeal airway leading to airway obstruction is the most common cause of the obstructive sleep apnea. In others, small chin (micrognathia), large tongue (macroglossia), or structural obstruction of the airway may cause symptoms. Children who have these difficulties often experience snoring, struggling respirations, and failure to thrive because of poor feeding. When the craniofacial malformations are also associated with abnormalities of the cerebral cortex or brain stem, then other sleep-disordered breathing patterns, such as central apnea and hypoxia, can occur.

NEUROMUSCULAR DISORDERS

Although abnormalities in breathing during sleep will be unique in each neuromuscular disorder, there are many common features. In non-progressive neurological disorders such as cerebral palsy, post traumatic syndromes, and certain myopathies, the degree to which the muscles involved in breathing and the muscles that control cardiorespiratory functions are affected generally dictates the symptoms. In cerebral palsy, for example, muscles of the upper airway (tongue, soft palate, pharynx, larynx) may be spastic while the child is awake. Upon falling asleep, the child's muscles may lose their tension and become hypotonic, which can result in obstructive sleep apnea and hypoventilation.

In children with progressive neuromuscular disorders, sleep-disordered breathing and respiratory failure may worsen over time. Many myopathies, spinal muscular atrophy, and Duchenne's muscular dystrophy are just some examples of progressive neuromuscular diseases that may contribute to disordered breathing. The presenting symptoms will depend on which muscle groups are affected, i.e., the intercostals (those between the ribs), abdominals, or diaphragmatic, but all generally result in both hypoventilation and hypoxia.

Any sleep-disordered breathing pattern can also result in a change in sleep stages—the consecutive physical stages that the body goes through during sleep. Nocturnal hypoxia, frequent nocturnal arousals, and prolonged apnea can result in daytime fatigue, behavioral problems, academic failure, and even developmental delays. On occasion, these disturbances can cause a disruption in a child's circadian rhythm—the body's sleep/wake cycle—causing the child to sleep during daytime hours and remain awake at night, further altering the sleep pattern.

Evaluating children for sleep disorders

The precise diagnosis of the underlying disorder will determine exactly the extent and type of evaluation that needs to be done. The child's medical history, including family history, is extremely important along with a complete list of the child's current medications. Chronic medical problems such as frequent middle-ear infections, hearing abnormalities, and recurrent tonsillitis can be at the heart of some sleep problems.

Snoring, sleep apnea, restless sleep, or mouth breathing are all features of an abnormal breathing pattern. Changes in daytime behavior, such as increased aggression, lack of coordination, hyperactivity, and excessive daytime sleepiness, are relevant. Academic failures, especially those associated with difficulties in concentration, are also meaningful. Fears and phobias are often part of a normal developmental pattern, but if they become excessive, they may be related to sleep-disordered breathing.

Physical exam

A thorough exam of the chest and the airway is essential to a proper diagnosis and treatment plan. Laboratory tests may include blood pressure and oximetry measurements (oxygen levels), x-rays, and blood gas determinations at various times of the day.

One of the most important tests is generally a nighttime polysomnogram, a non-invasive measurement performed in a pediatric sleep-apnea laboratory. The parameters studied may include: multi-channel EEG (electroencephalogram measuring brain activity during the different stages of sleep); monitoring leads on the chin (to measure mouth and airway activity) and on the legs (to measure any restlessness); video monitoring, electrocardiogram, chest and abdominal movement recordings, snoring microphone, oral and nasal air flows, amounts of carbon dioxide exhaled, oxygen saturations, and body position.

Treatments

Once the extensive evaluation has been done, treatment will depend upon a precise diagnosis of the sleep disorder. Various treatment protocols may include:

A. Sleep hygiene: This is a key component of treatment plans for all children with sleep disorders. Having a consistent daily bedtime routine with a regular sleep/wake cycle is necessary. Try to avoid allowing the child to be exposed to overstimulation in any form, including physical and dietary. Violence in any form should be avoided, including that seen on TV shows, threats, orders, or demands. A night light may help with the child's orientation if he awakens. Fear of the dark, separation anxiety, fatigue, and overstimulation, can act as a "trigger" to a child with a sleep disorder, especially those who have a neurological impairment. Tactics for responding include: quieting, comforting by talking, singing, rubbing the back or stomach, or reading a non-stimulating book quietly. Always put a child back to his or her own bed and stay until the child is calm.

B. Medication: On occasion, various drugs may be helpful in treating certain sleep-disordered breathing patterns. Methylxanthines can be useful for the treatment of central apnea or hypoventilation only. Drugs in this category would include caffeine or theophylline. They affect the body by increasing the respiratory drive, increasing the body's and brain's sensitivity to carbon dioxide and helping to increase diaphragmatic effort.

Treatment with melatonin is controversial, even though this chemical occurs naturally in our bodies. The body's production of melatonin may regulate our circadian rhythm, but in some children, especially those with prior neurological problems, it may precipitate or aggravate seizures. (Our own personal experience is that it can be beneficial, but often must be used in low doses.)

Benadryl® and diazepam are of some benefit in limited instances, especially when children are affected by severe night terrors.

Although phenobarbital is usually known as a sedative in children with neurological challenges, with or without seizures, it often may have a paradoxical effect. In these unusual situations, the drug would cause excitement rather than sedation. It is often given only in the morning, rather than at night time, if this unwanted side effect occurs.

C. Surgery and other invasive techniques: For children with obstructive sleep apnea, an example of a non-invasive technique is positioning with the head of the bed elevated, which may be helpful in some instances. Administration of oxygen by nasal cannula (tube that fits into the nostril) may decrease the severity of the hypoxia during obstructive events. However, the vast majority of children with obstructive sleep apnea syndrome will benefit from more invasive treatments. When tonsillar and adenoidal hypertrophy is the cause of the obstruction, either specific tonsillectomy or adenoidectomy may be helpful. In children whose muscle tone is a problem, or where the obstructive sleep apnea persists, despite surgery, the use of an oxygen mask that supplies continuous positive airway pressure (CPAP or BiPAP) may be needed. In rare instances, the use of a tracheostomy or even a respirator can be life saving.

Getting a good night's rest is vital for everyone, especially children whose bodies are challenged. If you suspect that your child has sleep-disordered breathing, discuss your concerns with your child's pediatrician. The diagnostic tests that were described here can be performed in a pediatric sleep lab and may yield an appropriate diagnosis and treatment. ■

This month's guest columnists, Frank P. Manginello, MD, FAAP, and Mary T. Carbone, MD, FAAP are clinicians at Valley Hospital, Ridgewood, N.J. Dr. Manginello is the Director of Neonatology and the Medical Director of Child Development. Dr. Carbone is the Director of the Pediatric Sleep Apnea Program.

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Circle #28

The Transition Journey

Useful tips to navigate the process and end up at a great destination

by Kerry McKenna

Based on experience of what has worked, transition from secondary school can be looked at not as an end in itself, but as a process that depends heavily on communication and cooperation between students, parents, and professionals. The ideas presented can give parents and professionals a snapshot of how transition planning can be improved so everyone benefits.

Transition Services have been a part of the IEP (Individual Education Plan) process for eight years now. Though we all seem to have a sense of what transition-services planning is for, it has become clear that making it happen is difficult. Looking back, one stumbling block may have been the focus on the "regulation" that mandated transition services. We wanted it to have a structure that would be in compliance with the federal regulation.

To use a metaphor, focusing on the regulatory elements was like trying to put the walls on a building without a frame or foundation. There was nothing to build on.

Slowly we have been learning that transition is not a thing. It is a process, a journey. It has a beginning, middle, and an end. It may take a while to reach "the end." It takes place over time. And most important of all, it is centered around each individual student. As we have come to grips with this process-style transition, we have learned that the start process should not be driven by which "slots" or openings are available at a school or agency. It should not be about fitting students into a system. It should be about making the systems become flexible to meet the student's needs The only way we can do that is to know the student.

This student-centered discussion needs to focus on the students' strengths and abilities because the reality is, those are the things that the student will market to the world as he or she find his or her niche in the community (And we all have our niche out there!). The student is the secret to success. So after all these years, we have learned some very important lessons:

- **Communication is the foundation to a successful transition-services process.** The foundation is a quality student-centered discussion. The core members of this discussion are the student (the center), the parents, and the school system. Others should be asked to join the process if they bring a positive contribution to the table. For example, a student who is receiving counseling outside of school may choose to invite the counselor to be a part of a strength-based discussion.
- **The IEP annual review meeting is not an appropriate forum to have a quality discussion about transition.** Both the transition services process and the IEP development process are best served when the transition discussion occurs well before the IEP annual review. Federal regulations dictate an "outcome-oriented process." Though each shool system may have a different name for it, the process is set out in an outcome statement (the student's desired goals and how he or she will achieve them). The outcome statement should be developed at this meeting. There are some distinct advantages to this process.

-It reduces pressure. It is less formal (structured but not regulated).

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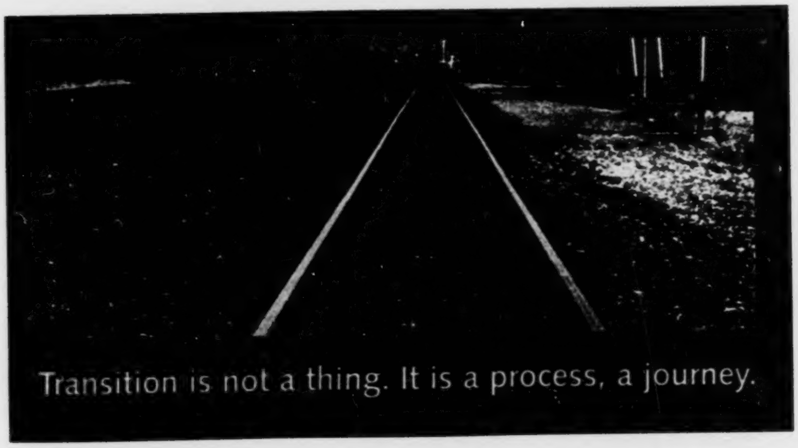

Transition is not a thing. It is a process, a journey.

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-It allows the student, parents, and school to all become comfortable with the outcome statements.

-It enables all the parties to have a sense of what the IEP should look like prior to the annual review meeting.

- **The transition services process is a tool for building hope.** It is a concrete way for the student to see a direct connection between his or her hopes and dreams, abilities, and the education process. The transition-services process message is very clear and simple: All students have a place in their community. For a person to find their place is not an easy road, with or without a disability. And for some, the journey is a life-long endeavor. A quality transition-services process allows the student to see a connection between dreams, abilities, and supports.

So, the student, parents and educators have a simple starting point: does the student leave the school system prepared for the community or unprepared? And yes, each party has to define what he or she means by prepared.

Although the student is the center of the process, success comes collaboratively. We all need support systems to succeed. A good transition process defines the supports a student needs in the light of the student's strengths.

- **If you don't know what you want, you can't get it.** Over and over, we are involved in discussions about "things" (i.e., more related services, less related services, needs to learn to read, needs to get into college) with no connection to the student. It is critical to stop and ask, "What is the goal?"; "How will the involved parties define success?" And as difficult as it may be, success needs to be defined in a way that can be measured. Words like "good"; "appropriate"; "do a good job" do not define. My definition of "appropriate" may not be your definition. We can develop accountable statements only by communicating to each other what we value.
- **Start early. Think long**. The transition regulation indicates that the process should start at age 14. There is nothing wrong with using the middle school years to make sure the student at least has an understanding of his or her own abilities. Some community services have long waiting lists, and other services have yet to be developed and require lobbying by consumers, parents and educators. These all take time and effort. Start early and make time a resource, not an enemy.
- **Transition-services process is a future-oriented discussion.** Its intent is not to talk about next year, but about the student's life after graduation when he or she goes out into the community. So, the student, parents and educators have a simple starting point: does the student leave the school system prepared for the community or unprepared? And yes, each party has to define what he or she means by prepared.
- **Transition planning is planning a route to a destination**. When a family leaves on vacation, they choose their destination before they leave and choose a route to get to there. They can change the route to avoid traffic or visit a friend. Transition wants you to set a destination for the education process. It can change since it will be reviewed every year, but setting a destination is important.

Learning for the future

We all may have to do things a little differently, like suspending our judgements based upon past experience (i.e.,when professionals and parents think things such as: "Students with developmental disabilities go to sheltered workshops." or "All my other children went to college"). We all need to learn to trust each other. Trust is not a regulation.

Please note, transition services are easy. But it is time to learn from the lessons and mistakes of those who are trying to make transition services a useful tool not just for the student, but for everyone involved in helping the student succeed. ■

Kerry McKenna is the facilitator for the Hudson Valley Transition Coordination Site at the South Westchester, NY BOCES. He provides technical assistance to students, schools, families, and agencies involved in the transition process.

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Martha Ziegler: EXCEPTIONAL PARENT HALL OF FAME

Lessons From the Front Lines

EP Hall of Famer has led the fight for good educational programs for all children with special needs and their parents.

Martha Ziegler, flanked by her son Fred and daughter Mary Ann, is a true pioneer in legislation for people with disabilities.

PART 2

Martha Ziegler, the founder of the Federation for Children With Special Needs, recently shared with EP her experiences in searching for an appropriate education for her child. Martha has used her experiences to help other children with disabilities and their families. The following is in Martha's own words. Segments where we have paraphrased her comments appear in italicized type.

Educating Mary Ann

"When we came to Lexington, (Massachusetts), I realized that we were paying exorbitant taxes to educate our son, Fred, and they were not being used to educate our daughter. I took her to the special education director that summer and said, 'Here she is—she's all yours.' Mary Ann, who has autism, was placed in the public school in Lexington in a segregated class that was held in the school's basement. The other children in her class had behavioral and emotional problems. I don't think any of the others had autism. Class was dismissed an hour early every day. The class got dismissed an hour early because the teachers were worn out, not the kids. Once in awhile, the teachers would call me in and say, 'Mrs. Ziegler, Mary Ann doesn't want to learn today. Would you come and get her?' I would go."

Pay attention to your child and see what they are interested in, what they want to talk about.

The special education program in Massachusetts at the time was based on categorical "labels." Each disability had its own set of laws and its own funding, and the amount of money allocated to each category was not distributed equally. When Martha's daughter started school, they had just added learning disabilities as a category.

"At Clark Junior High School, we met a terrific special education teacher. She had her doctorate from the University of Oregon, which at the time was a leader in special education. She decided that Mary Ann should be integrated. To prepare, she carefully trained the teachers (who would have Mary Ann in their class). At that time, there was tracking, so she made a smart decision and put Mary Ann in with the smartest kids, knowing that they would not feel threatened. The second thing that happened in junior high was that Mary Ann noticed her friends were learning Spanish. So she decided that she, too, wanted to learn Spanish! I thought that was strange because she still did not have much mastery of English! However, she took Spanish for five years, right into high school. Now she is as fluent in Spanish as she is in English, maybe even more so."

"When Mary Ann got to high school, I had to get very involved. The school tried very hard to keep her integrated, but it became increasingly difficult. The high school was very departmentalized, and most teachers had no training in how to teach kids individually. Mary Ann ultimately was placed in a special education program, but continued her Spanish classes and decided she wanted to take a science course. Finally, they let her take biology, and she achieved a B. I remember that during a parent-teacher conference, her biology teacher could not get over how well she was doing!"

"The biggest thing that I've learned from my daughter's education is that it is very important to build on a child's strengths. For example, academic efforts like learning a foreign language and learning Biology built on Mary Ann's exceptional ability to memorize. That she did so well in those classes opened my eyes to the fact that she should have been taking all the courses in

Labeling is really pitting parents against one another, all of them fighting for a piece of pie. It also builds a very strong barrier against genuine funding reform and feeds into the stereotypes at every level.

school that rely on memory."

"At the high school, Mary Ann also wanted to sing with the school choir and with a small group of about 12 girls, but the music teacher didn't think she could do it. I convinced the teacher to let her join, and she became one of Mary Ann's biggest fans! The choir was also a great experience for Mary Ann because she learned how to behave as a member of a group."

"My favorite story about Mary Ann goes back many years. At that time, a popular toy was a life-sized parrot that had a tape recorder in it. You talk to the parrot and he repeats back to you precisely what you said. I thought, 'This is great! It will help her understand how it feels when somebody keeps repeating things over and over.' I got her that parrot, and not only did it work as an example to help change her behavior, she taught it Spanish! The parrot learned Spanish very well. Pay attention to your child and see what they are interested in, what they want to talk about."

"Once, Mary Ann went to camp where they used role-playing as a teaching device to help children with autism learn appropriate behavior in social situations. She really enjoyed it and learned a lot."

Chapter 766: a beginning

The Federation for Children With Special Needs was the result of tireless work and a dose of good fortune. For 25 years, the Federation has been an important contributor to the lives of children with disabilities and their families. Martha talks about the Coalition for Special Education (of which she was co-chair) and the work that began after the passage of Chapter 766. Chapter 766 was one of the first comprehensive state laws mandating individualized education for children with disabilities.

"The Coalition for Special Education continued to be active for some time after the 766 law was enacted in July 1972. Then Betsy Anderson (co-chair of the Coalition) and I realized the work had just begun. What a lot of people don't realize is that although 766 was enacted in 1972, it did not take effect until September 1974. In that two-year period, there was significant activity in the state legislature. Bob Audette came here to serve as State Director of Special Education, and he worked very hard to develop regulations. We had a significant grant that led to two years of training for teachers all over the state. Materials were produced, and teachers were brought up to speed and ready to implement the law."

"It was while Betsy Anderson and I were working with Easter Seals that we really got started with parent advocacy. In the winter of 1974-1975, the Federation for Children With Special Needs was established. The Federation got legal assistance from a lawyer, David Trott, who was working under a fellowship at Harvard's Graduate School of Education. The fellowship program enabled David to work one year for the Federation. We received a pilot contract;, which was significant because it enabled us to open our doors to serve parents and the public."

A word of warning

Although classifying and labeling children with special needs is often seen as a way to help them, Martha points out that it engenders stereotyping of the children, and also serves to break up the one group whose solidarity is crucial to the success of any educational program: parents.

"There is a very great danger that Massachusetts will go back to the use of categorical labels. I know from other states that when you do that, parents have to fight to get the 'right' label. Programs are developed and run on the basis of the label and it moves you away from the needs of the individual child. Labeling is really pitting parents against one another, all of them fighting for a piece of pie. It also builds a very strong barrier against genuine funding reform and feeds into the stereotypes at every level. Initially, I did not see the importance of that. As time went on, especially after the federal law was enacted without going in that direction, I came to understand the importance of staying away from labels."

"If Mary Ann had been put in "autism" classes, she'd be nowhere today. That's another thing that people don't understand. In Massachusetts, getting rid of the labels really did lessen the stigma. I will never forget one time, about ten years ago, when I had to go to a drugstore in Lexington. It was during the annual fight over 766, and I had forgotten to take off the button that read 'Save 766.' The young man at the checkout counter looked at the button, smiled and said "Oh yes, I am in that program." I think he went to Minuteman Vocational Schools. That wouldn't have happened 15 years earlier. Back then, nobody said 'I am in a special education class.'"

Mary Ann Ziegler today

"Today, Mary Ann is in a supported employment program. She could easily keep a permanent position, but has had some setbacks because of her employers moving or going out of buiness."

"The other day, we were having lunch at a McDonald's and she saw a 'help wanted' sign, so she will most likely be working there soon."

Mary Ann and Martha have lived through a period during which great strides have been made for the rights of people with disabilities. As a pioneer of this legislation, Martha can look back and see how far her daughter—and the state—have come. ■

For more information on the Federation for Children with Special Needs, you can contact them at 1135 Tremont St., Ste. 420, Boston, MA 01210; Telephone: (617) 236-7210; (800) 331-0688 (in MA); Fax: (617) 572-2094; Web site: http://www.fcsn.org.

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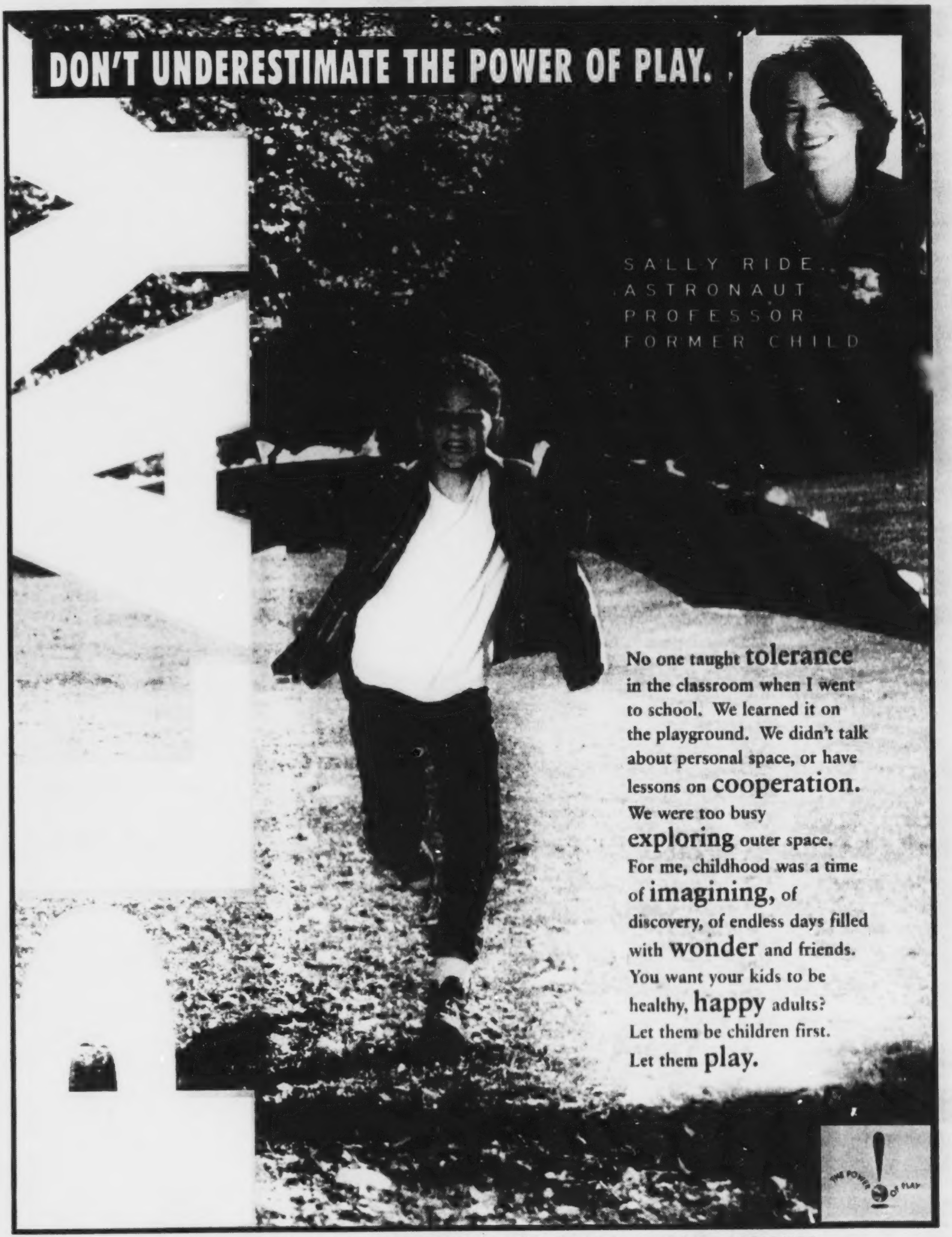

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No one taught **tolerance** in the classroom when I went to school. We learned it on the playground. We didn't talk about personal space, or have lessons on **cooperation.** We were too busy **exploring** outer space. For me, childhood was a time of **imagining,** of discovery, of endless days filled with **wonder** and friends. You want your kids to be healthy, **happy** adults? Let them be children first. Let them **play.**

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PART 2

Tech For TOTS™:

Assistive Technology for Infants and Young Children

by Sonia K. Aller, PhD, CCC and Toni Solano, MBA

Assistive technology (AT) plays a key role in enabling infants and young children to develop the skills they need to learn and grow. However, getting an assessment and funding source to pay for necessary equipment can sometimes be a major barrier. The following article discusses a child's right to AT under the law, who can assess a child's needs, and who can provide funding for AT.

Potential AT users

Children ages birth to 3 (or birth to 9 if the state and local education agency agree to provide such services) who may be entitled to early intervention services, including assistive technology, are those who are identified as experiencing (or at risk for) developmental delay in: physical development, cognitive development, social or emotional development, and/or adaptive development.

For example:

- Mental retardation
- Hearing impairments, including deafness
- Speech or language impairments
- Visual impairments, including blindness
- Emotional disturbance
- Orthopedic impairments
- Autism
- Traumatic brain injury
- Other health impairments
- Specific learning disabilities

These conditions are covered under the Individuals with Disabilities Education Act (IDEA). If a child meets the eligibility requirements within these categories for special education services, AT always should be considered for the child's Individualized Education Program (IEP).

Prior to assessing a child for AT, the child should have his or her developmental and educational abilities assessed.

To get a true picture of the child's abilities and areas of weakness, the assessment should include, or at least take into account, the child's performance given adaptations, modifications and assistive technology not currently in use.

Assistive technology should not be a last resort after all else has failed; neither should it be regarded as a cure-all. Moreover, AT should not replace other kinds of intervention. For example, a child who is given a walker should continue to receive physical therapy aimed toward independent walking.

Legal requirements:

IDEA: The Individuals with Disabilities Education Act Amendments of 1997 mandate that AT be considered in a child's IEP and Individualized Family Service Plan (IFSP) when identifying appropriate early intervention or school services for the child.

While many think of AT solely as a device, assistive technology also includes the services necessary to select, acquire and use the device, including:

- The evaluation of the needs of a child with a disability, including a functional evaluation of the child in the child's customary environments;
- Purchasing, leasing, or otherwise providing for the acquisition of assistive technology devices by a child with disabilities;
- Selecting, designing, fitting, customizing, adapting, applying, maintaining, repairing, or replacing assistive technology devices;
- Coordinating and using other therapies, interventions, or services with assistive technology devices, such as those associated with existing educational and rehabilitation plans and programs;
- Training or technical assistance for a child with a disability or, if appropriate, that child's family; and
- Training or technical assistance for professionals (including individuals providing education or rehabilitation services), employers, or other individuals who provide services to, employ, or are otherwise substantially involved in the major life functions of that child.

Section 504 of the Rehabilitation Act of 1973: This legislation states that children with disabilities must have the same opportunity to benefit from a program or service as a child without disabilities, as long as the "provider organization" receives federal funds. The provider organization may be a public school, a charter school, or a private school. What counts is whether or not the organization receives federal funds of any kind, for any reason, not necessarily having to do with the child's programming. For example, the school may receive a federal grant to reroof the building. Under the Rehab Act, the school still would have to comply.

This act contains a broader definition of what constitutes a disability than IDEA. Under the Rehab Act, a person is considered to have a disability if he or she:

- Has a mental or physical impairment that substantially limits one or more of such per-

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Circle #17

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son's major life activities;

- Has a record of such impairments; or
- Is regarded as having such impairments.

Americans with Disabilities Act

This legislation also provides accessibility rules, such as sidewalk curb cuts, wheelchair ramps, grab rails in restrooms, and wheelchair accessible doorways.

A team approach to AT

Children with disabilities frequently have needs involving several disciplines. Only a coordinated effort by a team of professionals and family members can ensure a proper assessment for AT devices and services. The members of the transdisciplinary team may include: parents/family members; teacher/principal/program director; occupational, physical and/or speech-language therapist (who each bring knowledge of the child's strengths and needs within their domains); AT specialist (a professional with specialized knowledge of the technology tools that can aid the child in the areas outlined by the team); pediatrician/nurse/other medical professional; rehabilitation engineer (a specialist in customizing a device for the child's use); social worker/service coordinator/case manager. Here is an example of a well-executed transdisciplinary team approach:

- Prior to meeting with the AT team, the child has had a good developmental assessment, which has been provided to the team, and which each team member has reviewed.
- Areas of concern by the referring party (parents, caseworkers, early intervention program, etc.) have been written and distributed to the team.
- An assigned case manager would meet the child and parents, explain the process and set up an assessment schedule with the child and parents and the other team members.
- Individual team members will have the opportunity to observe, question, and assess the child and consult with the parents and each other.
- The team members, not including the parents or child at this time, meet as a group to resolve final questions and draw up recommendations. These recommendations should include at least three devices, features lists, pros and cons of the device for this child, sources and prices. Findings and recommendations are relayed to the parents at a final meeting, where all team members present their piece and are available to answer questions.
- Decisions are made as to how to go forward, and responsibilities are assigned for funding the device, getting the device, adapting or fitting the device, providing training to all necessary parties, and implementing use of the device.
- At this meeting, a follow-up evaluation is scheduled, at which time the child's use of

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FUNDING EXCUSES

Parents, and even the professionals who work with parents in getting funding for AT for their children are destined to hear these at some point. They may feel they have no recourse, but those who are well-informed know these excuses may not always be valid.

Top 10 excuses for not funding AT

1. "The law says we cannot help you."
2. "Your child is not eligible for services from this agency."
3. "Talk to your insurance company."
4. "Our professional experts do not agree with your assessment of your child's needs.
5. "We do not agree these needs could be met by AT."
6. "Although this type of device would be optimum for your child's needs, we are not required to provide this level of service."
7. "We would like to provide you with funding, but we have limited resources."
8. "What you want costs too much. We have limits on what we can spend on a single client."
9. "We are a payor of last resort, so come back to us after you have exhausted all other resources."
10. "We can put your child on a waiting list."

RESPONSES to Top 10 excuses for not funding AT

The following are some suggestions on which to base a response to each excuse:

1. In fact, the law may say the funding agency is supposed to help you. Their representative may not know this, or may be misled. Find out to which law they are referring, and check for yourself.
2. Find out in writing what the eligibility requirements are; perhaps a referral can be rewritten in the language the funding agency requires.
3. Personal health insurance may be a funding option, but that does not relieve the agency from also performing.
4. The counter to this argument is for a member of the child's AT team to write an assessment that reflects the team's thinking.
5. Once the AT team professionals have deciphered the level of service the agency is required to provide, they can make a recommendation that the agency can support.
6. A response to this must be based on what the level of services the agency is required to provide. Find out in writing the legislation and/or policy that documents those services.
7. In the case of schools and certain other agencies, lack of resources is not a legal excuse.
8. Parents can check their insurance policy, (or ask the help of one of the professionals on the AT team to do so), or the professionals on the AT team can check the agency's policies to validate this argument.
9. This might be true, get this in writing and check against the agency's policy.
10. Waiting lists, though they exist, are not always legal. Advocacy organizations can shed light on the legality of waiting lists in your state.

RESOURCES

CONFERENCES

Center on Disabilities, California State U., Northridge
Holds Technology and Persons with Disabilities Conference in Los Angeles in March
Phone V/TDD: (818) 677-2578
Fax: (818) 677-4929
E-mail: ltm@csun.edu
Web site: http://www.csun.edu

Closing the Gap Conference, Held in October in Minneapolis
Closing the Gap
Phone V: (507) 248-3294
Fax: (507) 248-3810
E-mail: info@closingthegap.com
Web site: http://www.closingthegap.com

RESNA,
Holds conference and information on State Technology Act programs
Phone V: (703) 524-6686
TDD: (703) 524-6639
Fax: (703) 524-6630
E-mail: info@resna.org
Web site: http://www.resna.org

The Council for Exceptional Children,
Holds "Children, Technology and Media Conference and also provides advocacy
Phone V: (888) CEC-SPED
TDD: (703) 264-9446
Fax: (703) 264-9494
Web site: http://www.tamcec.org

SOURCES OF AT MANUFACTURERS

ABLEDATA
Database of thousands of AT products
Phone V: (800) 227-0216
TDD: (301) 608-8912
Fax: (301) 608-8958
Web site: http://www.abledata.com

Dreamms for Kids, Inc.
Assistive technology product links
Web site: http://www.dreamms.org

ADA PROJECTS

10 federally funded regional resource centers (Disability and Business Technical Assistance Centers) on (ADA), providing information, technical assistance and referrals for implementing the ADA.
Phone V/TDD: (800) 949-4232
E-mail: adata@adata.org
Web site: http://www.adata.org

Adaptive Environments Center, Inc.
National Access for Public Schools Project
Helping school systems across the country come into compliance with ADA.
Phone V/TDD: (617) 695-1225
Hotline V/TDD: (800) 893-1225
Fax: (617) 482-8099
E-mail: adaptive@asaptenv.org
Web site: http://www.adaptenv.org

ADVOCACY ORGANIZATIONS

Disability Rights Education and Defense Fund, Inc. (DREDF)
Phone v/TDD: (510) 644-2555
Fax: (510) 841-8645
E-mail: dredf@dredf.org
Web site: http://www.dredf.org

Easter Seals National Office
Phone V: (800) 221-6827
TDD: (312) 726-4258
Fax: (312) 726-1494
Web site: http://www.easter-seals.org

United Cerebral Palsy Associations
Phone V: (800) 872-5827
TDD: (202) 973-7197
Web site: http://www.ucpa.org

Alliance for Technology Access Centers
Phone V: (415) 455-4575
TDD: (415)455-0491
Fax: (415) 455-0654
Web site: http://www.ATAccess.org

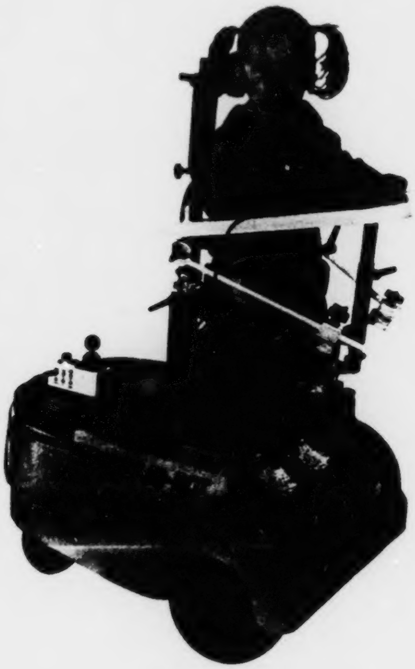
PARENT TRAINING AND INFORMATION CENTERS

Technical Assistance Alliance for Parent Centers
PACER Center
Phone V: (888) 248-0822
TDD: (612) 827-7770
Fax: (612) 827-3065
Web site: http://www.taalliance.org

UNIVERSITY AFFILIATED PROGRAMS

American Association of University Affiliated Programs for Persons with Developmental Disabilities
Phone V: (301) 588-8252
TDD: (301) 588-3319
Fax: (301) 588-2842
Web site: http://www.aauap.org

University of Southern California
University Affiliated Program
Childrens Hospital Los Angeles
Phone V: (323) 669-2300
Fax: (323) 671-3842
Web site: http://www.uscuap.org



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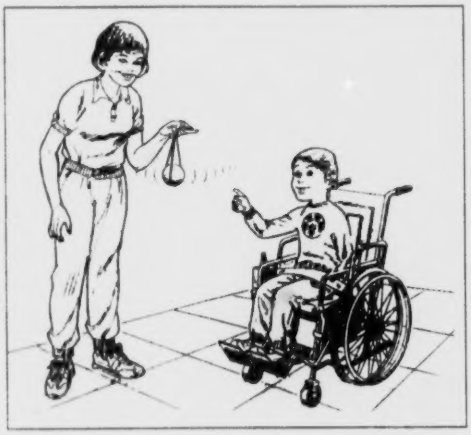
SPECIAL OLYMPICS

Motor Awareness, Mobility, and Dexterity Exercises

Some easy movements, and excercises can help build and improve motor awareness, mobility, and dexterity. These exercises can be performed independently, or if necessary, with assistance.

Motor awareness activities can enable individuals to learn body awareness and helps them practice responding to visual, auditory, and tactile stimulation—all of which are needed as a foundation for participation in games and sports.

Activities that are of interest to a the participant and that are within his or her abilities will be more enjoyable. Individuals who master all of the steps relating to a particular skill may wish to consider training for a specific sport. (Note: No exercise program should be started without physician approval.)



Motor Awareness Activities

With demonstration and practice, participants can gain awareness of visual, auditory, and/or tactile stimulation.

SUGGESTIONS FOR ACTIVITY COACHES

- Continually talk to the participant, preparing him or her for the stimulation and reinforcing him or her for paying attention.
- Encourage the participant to perform some of the activities independently or with assistance.
- Work with two participants together and foster turn-taking and interacting.
- Use age-appropriate objects with participants. For example, older participants should be given sports and adult leisure equipment and contemporary music for stimulation while younger children can use toys and games.
- Note that children who are prone to seizures may be sensitive to loud noises. Modulate voice, music, or other sounds accordingly.

Visually attending to objects, movement, and people

Place participant in his or her most comfortable and functional position. Provide support to participant's head, shoulders, neck, etc., as needed.

- Give participant a verbal cue: "look at (object)." Hold object in front of participant so that he or she can see it. Shake object to further stimulate participant.
- Once participant focuses on object, slowly move it from side to side, then up and down. Move it slowly enough so participant can follow it with his or her eyes.

Auditorily attending to sounds and voices

Place participant in his or her most comfortable and functional position. Provide support to participant's head, shoulders, neck, etc., as needed.

- Give participant a verbal cue to "listen for the sound." Shake bells, bang objects, or make noise in front of the participant close enough so that he or she can hear it. Start off softly so you do not startle the participant.
- Once participant focuses on sound, slowly move the object around. Repeat it with several different sounds, as well as with your voice.

Accepting and attending to tactile stimulation

- Give participant the verbal cue "I am going to touch you with a soft object."
- Starting with the head and neck, gently touch soft objects to the participant's arms and legs. Once participant focuses on the body part that is being stimulated, slowly move up and down that body part. Repeat with a variety of soft objects.

Mobility

SUGGESTIONS FOR ACTIVITY COACHES

Be extremely cautious and gentle when manipulating the participant. Do not move any of his or her joints or segments past their range of motion (stop when you feel resistance). Consult the teacher or therapist before attempting to physically manipulate participant.

Wrap the participant in blankets and unroll him or her to help understand rolling. Have two participants work together or compete against each other in a mini-competition.

Head lifting

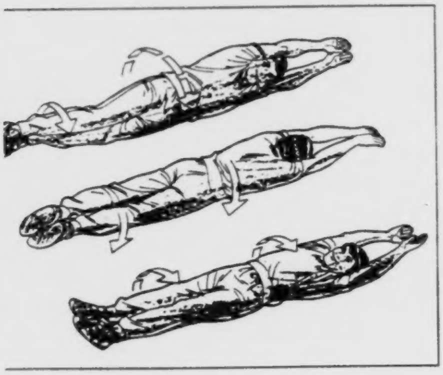
- Place participant prone on mat or soft surface.
- Give participant verbal cue: "lift your head."
- Shake brightly colored object or make sounds to stimulate participant to raise head.
- If participant does not lift head, gently stroke the spine area starting from the neck and going straight down the spine several times. Note that this elicits a reflex

reaction that lifts the head. It is not a voluntary action.

- As participant lifts head toward stimuli, gradually move stimuli higher and higher.
- Encourage participant to maintain head lift for five seconds or more.
- Repeat three to five times using various objects. Allow participant a 30 to 60 second rest in between trials.

Rolling onto back

- Place participant prone on mat or soft surface. Make sure arms are to side of body or above head (not tucked under chest or abdomen).
- Give participant verbal cue: "roll over."
- Shake brightly colored object or make a sound to the proper side of the participant to stimulate rolling.
- Assist participant by gently turning his or her head in one direction and pushing with the hand to which the participant is facing. Then gently turn participant's body over.



- Allow participant to, independently or with minimal assistance, perform as much of the activity as possible.
- Once participant successfully turns to back, allow him or her time to play with an object. Repeat entire procedure after a 60 to 90 second rest period.

Dexterity

The ability to successfully perform grasp and release activities is a skill used in many different sporting events.

SUGGESTIONS FOR ACTIVITY COACHES

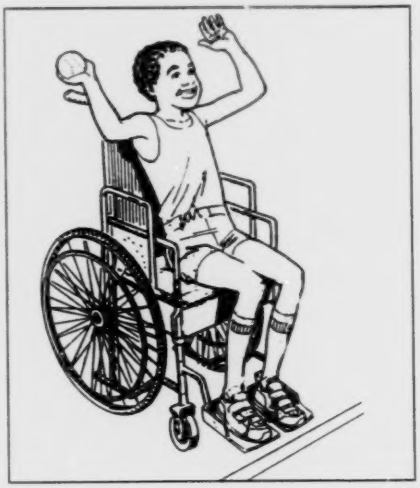
- Explore different positions for the participant both in and out of his or her wheelchair in order to find the most comfortable and functional position for grasping and releasing. If participant cannot use hands, explore other holding and releasing possibilities, such as using his or her foot. Experiment with different sized bean bags to find out which one is best suited for that participant.
- Allow participant to try all activities independently. If participant needs assistance, provide only enough to allow him or her to perform that particular aspect of the skill.
- Use a variety of objects to stimulate participant. Try to find objects that are easily grasped by the participant based on size, shape, and texture.
- Pair participants together to play games of passing an object around a circle or having relay races.
- Before participant performs any of the following activities:
- Place participant in his or her most comfortable and functional position for using his or her hands. Provide support to participant's head, shoulders, etc., as needed to ensure maximum function.

Grasping and holding a small object

- Give participant verbal cue: "grasp the object."
- Place object near participant's hand or in palm of hand.
- If he or she cannot open hand, gently push down on back of hand to help spread fingers.
- Once participant grasps object, encourage him or her to hold it for 10 to 20 seconds.
- If participant cannot release object, assist him or her in opening hand by pushing down gently on back of hand.
- Repeat with a number of different objects that can be easily grasped.

Grasping, moving, and releasing a small object

- Give participant verbal cue: "pick up the object and drop it on the target."
- Place object near participant's hand or in palm of hand.
- Allow participant plenty of time to independently attempt to move object towards target and release it.
- Repeat with a number of objects and encourage greater independence, speed, and accuracy. As the participant improves, gradually move the target farther away.



Tossing a soft shot put

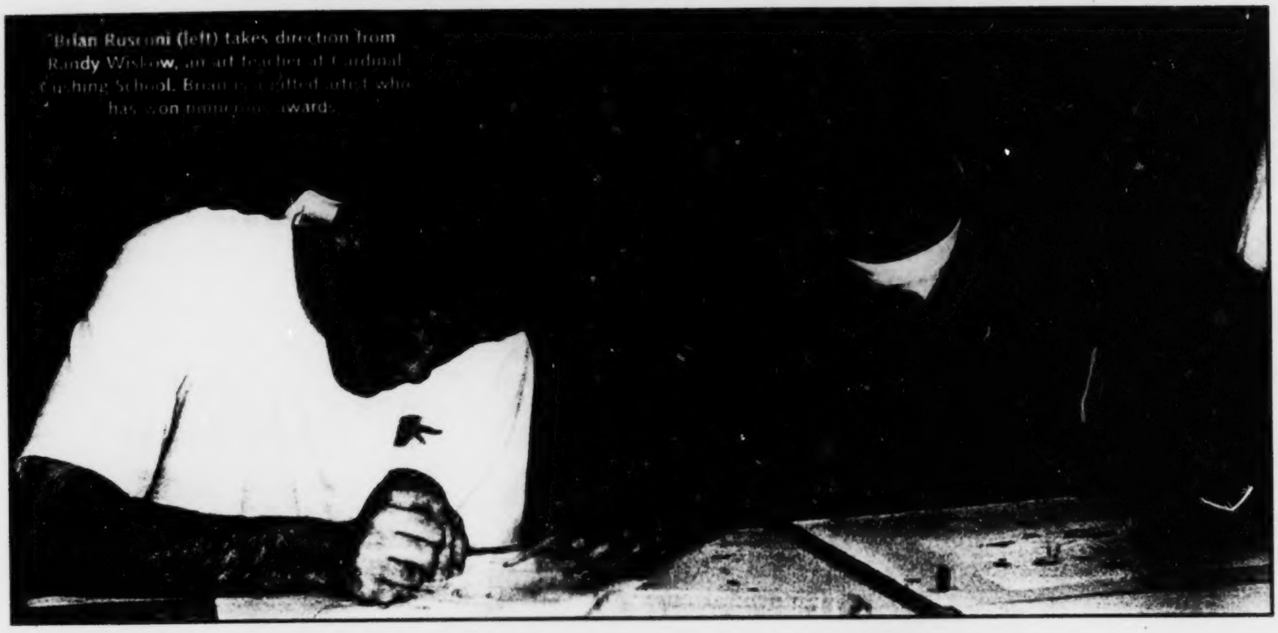
- Give participant a bean bag to serve as a soft "shot put" and encourage him or her to throw it as far as possible.
- Give participant verbal cue: "throw the shot put."
- Allow participant plenty of time to independently release shot put. If he or she cannot, gently assist by holding him or her at shoulder and forearm and moving arm in a throwing pattern.
- Repeat a number of times with various size soft shot puts. ■

Adapted from the Special Olympics "Motor Activities Training Program Guide."

For more information, contact:

Special Olympics International
1325 G St., NW, Ste. 500
Washington, DC 20005
(202) 628-3630
(202) 824-0200 (fax)
E-mail: soimail@aol.com
Web site:
http://www.specialolympics.org

THE ARTIST



Brian Rusconi (left) takes direction from Randy Wiskow, an art teacher at Cardinal Cushing School. Brian is a gifted artist who has won numerous awards.

as a Young Man

by Kerry Pianoforte

Brian Rusconi has always had a special gift for art. When he was a young child he would watch his grandmother paint at her easel, and eventually he started painting. At the age of seven, with no formal training, he won his first award for a watercolor he painted. According to Brian's mother Terry, he was always interested in art.

As a young child Brian was very visually oriented. He was more interested in collecting magazines and other trinkets than playing with toys. His family did their best to encourage him to pursue this interest. Terry says, "Anytime that we could involve him in any kind of art classes we did. My mother-in-law, who used to be an artist, worked with him." In addition to the help from his family, Brian was enrolled in a summer art program for three years.

Brian, now 17, is still receiving praise and recognition for his extraordinary artistic talents. Brian, who has Asperger syndrome, a type of high-functioning autism characterized by an inability to understand how to interact socially, has recently become proficient with charcoals and pastels. His work has been exhibited at shows alongside seasoned artists twice his age and he has received numerous awards. Brian's talent is apparent to all who view his work. Randy Wiskow, an art teacher at the Cardinal Cushing School and Training Center in Hanover, Massachusetts, a school for children who have developmental delay that Brian attends, noticed his talent immediately. "When he first got to school here he definitely had some talent. I noticed that Brian seemed to really enjoy what he was doing and he was having a good time, but he wanted to do more. I asked the teacher if I could have him down for one-on-one lessons. I introduced him to larger sheets of paper and that's when he started to just flow." Brian now does all

Brian uses a variety of media to create his artwork. "Meditation" and "Remorse" were made with charcoal, and "Untitled" was created using pastels.

"Meditation"

"Remorse"

his art, including his award-winning pieces, on these large, 24" x 36" canvases.

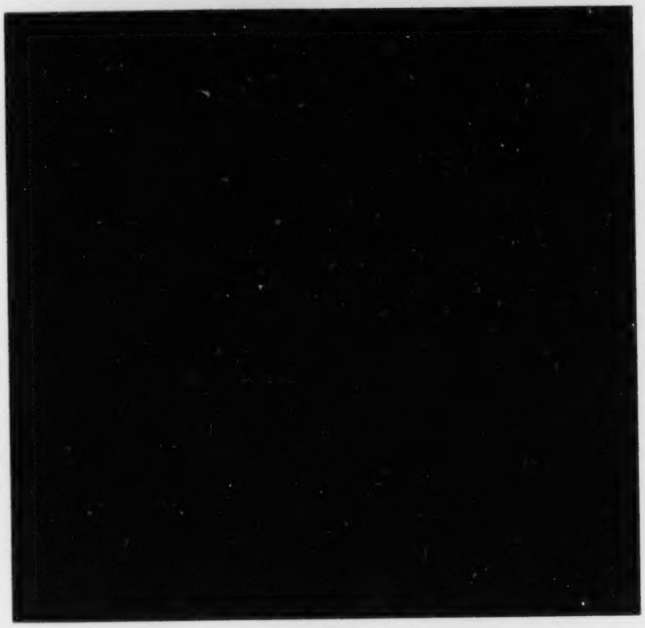
Brian's life is immersed in art. He now has a unique arrangement with the Weymouth public school. Every morning he is bussed there and mainstreamed into a high school art class. After this class, he is driven by his mother to Cardinal Cushing, where he completes the rest of his schooling. This arrangement has been successful for everyone.

Brian's mother feels that being mainstreamed for one period a day is great for his self-esteem. "He's gained the recognition from the other students as being a very good artist. They had a big art show last week, and all his paintings were up. Kids were going up to him and patting him on the back. They were regular seniors who were graduating. Many of them were going to art school!"

Making the connection through art

Art offers Brian many benefits. According to his mother, Brian's disability makes it difficult for him to interact socially with others. His art allows him to reach out to others in a unique way. Students at Cardinal Cushing love to watch him draw and Brian will now draw pictures for them. His art also gives him an outlet for creativity and self expression. Brian's mother reports that his art has a therapeutic benefit. "It's relaxing for him; it's a therapy." In addition, the recognition Brian receives for his art helps bolster his self esteem.

Brian's mother, a special education teacher, feels his success is a result of heeding the advice her pediatrician gave her when her son was first born. "He told me that I should always find something that he can do really well, that he can excel at, and capitalize on it...accentuate what can be done instead of always trying to pick out negative things and then work on those." This sentiment is echoed in the philosophy of Cardinal Cushing School and Training Center. Randy explains, "We try here at the school to find some type of program that each student can excel in."



"Untitled"

Randy has his art students try many different types of media to work with such as clay, basketry, painting, or drawing. Randy says the goal is to "find something that they really like to do so they can continue doing that after they leave here."

A matter of perspective

According to Terry, one of the challenging behaviors associated with Asperger syndrome is the failure to recognize social cues. "No matter how many times you say something, it doesn't impact. With this syndrome there is also a lot of egocentricity. Often these kids get locked into something they really like and they just think that everyone else should like it. That's all they talk about."

"Locked" into art, Brian has taken something he is passionate about and turned it into a lucrative hobby. He has used the earnings from the sales of his work to purchase marionettes, another of his interests. When Brian was a sixth-grade student at a public school, he would entertain students with his puppets. He would put on shows for children who were deaf and his teacher would sign along. In addition to his art and puppetry, Brian is also a loyal attendee of the Boston Ballet Company. After seeing a performance, Brian will spend many hours on the Internet tracking down the music so that he can can enjoy a musical recreation of the ballet at home.

When asked what he sees himself doing in the future, Brian replies, "I want to work for the Boston Ballet as an illustrator." With Brian's talent, both his family and teachers are optimistic that he will continue his artistic endeavors after he graduates. ■

EDITOR'S NOTE: Special thanks to Jane Spitz and the Cardinal Cushing School and Training Center.

Though he experienced fine motor problems, Mason Barney was always interested in pictures. As a sophomore in college, he discovered his talent and a new way to express himself.

Computer Technology Can Empower Students with Learning Disabilities

by Leslie B.G. Goldberg
and Lucinda M. O'Neill

Mason Barney was classified as a "gifted" student, so why was he failing math? When his parents met with his third-grade teacher to review his tests, they discovered something unusual. "Although Mason was only answering half the questions, he was getting all the completed ones correct," says his father, Jim. "We knew something was wrong."

They soon found out that Mason had a severe learning disability, including problems with reading, writing, organization, and attention—learning barriers that impaired his performance in all subject areas. In math, for example, Mason had trouble both reading word problems and recalling quickly enough the formulas and other basic knowledge necessary to complete tests and quizzes in the allotted time.

His parents immediately enlisted support from special needs experts, but not without some opposition. "One psychologist told us it was impossible for Mason to be gifted and learning disabled at the same time," says his mother, Bonnie.

Then several teachers recommended CAST, the Center for Applied Special Technology in Peabody, Massachusetts, not far from the family's home. In 1986, 9-year-old Mason enrolled in a CAST summer computer camp for students with disabilities. His parents watched, amazed, as Mason's brilliance found its voice through the computer. His confidence blossomed as CAST clinicians taught Mason to use graphics software and word processing to express himself, and learning software to support his lagging skills. It was the beginning of a long and rewarding relationship for both Mason and CAST.

CAST invited Mason to join its Pioneer Program, a research and development initiative that explored the role computers can play in supporting learning in children with physical challenges, hearing and vision impairments, and learning disabilities. The valuable insights that CAST researchers gained from their work with Mason, and other young "Pioneers," provided a solid foundation for what later evolved into the Universal Design for Learning™, the organization's conceptual framework for responding to individual learner differences through the use of multimedia technology. Mason has been providing insight into the role of Universal Design for Learning (UDL) in addressing learning disabilities ever since.

Using technology in the classroom

Once he started using a computer to help him with his schoolwork, Mason could access material in a variety of ways and get support for his reading, writing, and spelling. Suddenly, he had a new way to express himself as well as to keep moving ahead academically. In the Ipswich, Massachusetts public schools, which he attended through high school, Mason was fortunate enough to have teachers who endorsed his use of computer-based learning supports. Mason attributes his teacher's attitude to his reputation as a serious student and to the fact that he was careful to ask his teachers' permission before bringing his laptop computer to class. As technology began to be integrated school-wide into classrooms in the early 1990's, Mason's teachers gained a new appreciation for their student's advanced computer skills. They would turn to him for " tech support" when faced with problems beyond their own technical expertise.

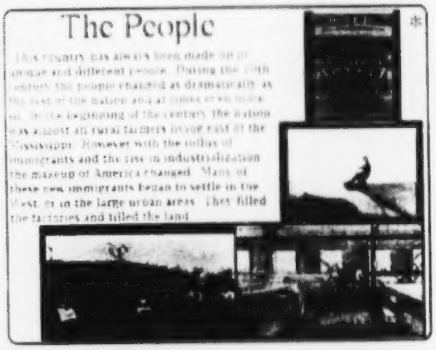
For Mason, who considers his spelling and penmanship to be "atrocious," multimedia was a "godsend." Instead of relying on words alone, he used pictures, sounds, and text to express ideas. Providing such "multiple means of expression" is a key tenet of the UDL approach to education, and contributed strongly to Mason's academic success. Rather than write a report for a high school assignment on 19th Century American society, Mason created a multimedia presentation using images, sounds and words. By using multimedia to reflect his research on the subject, Mason was able to get excited about the project and " really 'wow'" his teacher.

In fact, Mason's academic performance improved so much that he was accepted at prestigious Bowdoin College, graduating in 1999 with a double major in Computer Science and Studio Art. At Bowdoin, Mason relied on computers for virtually all of his coursework. He used digital versions of textbooks (when available) and did most of his research and reading on the Internet with support from the CAST eReader™, which reads any digital text aloud. While Mason was virtually the only kid in high school to bring a laptop computer to class, he became a trendsetter in college. After observing him typing notes on his Macintosh™ PowerBook during class lectures, almost a third of his classmates began toting their own laptops to class.

For his American Literature class, Mason found the works of Poe and Hawthorne online and used the CAST eReader to highlight text and read aloud. "I read very s-l-o-w-l-y," he says, drawing out the syllables. "What someone else might read in a day could take me a month." Using eReader, Mason was able to increase his reading speed dramatically and maintain excellent comprehension, as the As and Bs he earned at Bowdoin attest. Tools such as "spell check" were also invaluable to him. "I cannot spell to save my life," he says. "You can tell me how to spell something a million times—I still won't get it right."

At Bowdoin, Mason did more than read the classics. As a sophomore, he took an art class and discovered his talent for drawing.

continued on page 74



The People

This country has always been made up of unique and different people. During the 19th century the people changed as dramatically as the rest of the nation and at times even more so. In the beginning of the century the nation was almost all rural farmers living east of the Mississippi. However with the influx of immigrants and the rise in industrialization the makeup of America changed. Many of these new immigrants began to settle in the West, or in the large urban areas. They filled the factories and tilled the land.

Writing a report for a high school history assignment would have been next to impossible for Mason. Instead he created a multimedia presentation using images, sounds, and words; the image (second from the top) is actually a digitalized movie that Mason imported from a laser disk.

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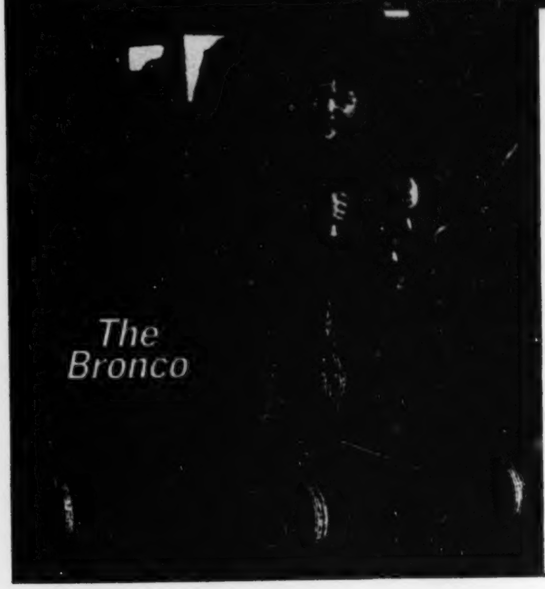

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At Bowdoin College, Mason Barney used his desktop computer or a Macintosh™ PowerBook for virtually all his coursework.

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"This was the first time I'd ever tried art. People assumed that because I had fine motor problems, I couldn't draw," he says. "But I've always been interested in pictures." Mason's mother recalls her son spending hours at museums and poring over National Geographic magazines. "We didn't realize he was getting all his information visually," Bonnie says.

Making it all work

Mason remains fascinated by the computer's ability to produce riveting visual effects. "I prefer material presented as text, speech, and pictures," he says. "With all those different representations coming at me, I'm able to 'get it.'" The computer is an ideal vehicle for such "multiple representations of content," another core UDL concept. Such built-in flexibility is central to the effectiveness of a universally designed curriculum. While some of this flexibility is derived from individual software programs, an essential part comes from the thoughtful gathering of tools, programs, materials, and Web sites that can be used in different combinations for different learners and for different teaching purposes. (For a complete description of the UDL concept, see "Tools and Materials That Support the Learning Brain," EP, May 2000, pp. 60-62.) As a student, Mason relied on Adobe® Photoshop® and the then-popular HyperCard program to create his multimedia projects. (Today, Mason says, he would use Microsoft PowerPoint® to produce similar presentations.)

Although Mason's self-esteem remained strong during his high school and college years, the frustrations were, at times, overwhelming. "Even with all the help, I sometimes thought 'I'm just not capable,'" he admits. But positive past experience and motivation propelled him forward. "I've learned that computers can help you do almost anything," he says.

Facing the future

Mason is now reaping the benefits of all his hard work. At 23, he has embarked on a promising career as a Web site developer, and his learning disability has, "without question," led him in directions he might not otherwise have pursued. While it has closed some doors on his career path, it has opened others. "Though my job as a programmer isn't visual, my training as an artist has taught me how to think creatively," he says today. "My learning disability has given me a different view on a lot of projects. It allows me to see the angles others might have missed."

If there is one message Mason could convey to parents of children with learning disabilities, it is the importance of learning as much as possible and gathering outside opinions on the diagnosis. "Get support. Make sure you're not the only ones reading the [evaluation] reports." Becoming informed, he adds, " is important not only for the parent, but for the child, so he or she never gets the feeling, 'I'm just dumb. I can't do this.'" Mason credits his own parents for their unwavering support. "They've been my best advocates," he says. From the beginning, the Barneys recognized their son's potential and urged him beyond the many obstacles. "Sometimes we were the only people fighting for him," Bonnie says. "But when CAST got involved, they realized his ability to achieve and really encouraged him."

The Barneys' efforts have been well worth the struggle. In their hometown of Ipswich, Mason's former teachers are still inspired by his legendary computer proficiency, and his success has paved the way for other children with disabilities. Thanks to Mason's positive example, the Ipswich teachers have an increased awareness of the issues surrounding learning disabilities and the role computer technology can play in addressing these issues. As Mason's mother says: "Mason is a trailblazer. He's going to do wonderful things." ■

Leslie B. G. Goldberg is a Boston-based freelance writer and corporate communications consultant. Lucinda M. O'Neill is a staff writer at CAST.

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Resources

Parents of children with disabilities can obtain assistive technology, services, and information under the federal Technology-Related Assistance for Individuals with Disabilities ACT (Tech Act). For more information on local services nationwide, visit the Tech Act Web site at http://www.abledata.com/Site_2/state_technology_assistance_proj.htm, or call Abledatea at (800) 227-0216 (press 4 to talk to a represenative).

The Alliance for Technology Access Cneter is a national organization with centers thorughout the country. Many of these centers provide evaluation services; others can refer parents to evaluation centers in their area. They may be contacted at (415) 455-4575 or their Web site: http://www.ATAccess.org.

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There will be a physical therapy track that starts with a four-hour pre-meeting interactive session on Wednesday, September 20 and continues through two "breakfast with the experts." The orthopaedic track will start as a pre-meeting offering on Wednesday with an advanced level series of case presentations including an international faculty and will continue with two "breakfast with the experts" on Thursday and Friday. Bloorview Mac Millan Centre is offering the opportunity to visit the campus and view current assistive technology on Wednesday. The Director of the Rehabilitation Engineering Department will speak on the 30-year evolution of rehabilitation engineering on Friday.

Free papers include orthopaedic topics, muscle performance, psychosocial issues, autism and gait analysis. There will also be posters and guest speakers. 25 countries (not including the US and Canada) were represented at the 1999 Annual Meeting.

For more information, fax 847-823-0536 or e-mail king@aaos.org.
The program is posted on the AACPDM web site at www.aacpdm.org.

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RedBarn ENTERPRISES

Circle #58

continued from page 66

the device in his or her customary environments is observed, and further recommendations are made.

Funding resources

Generally speaking, if the IEP team or IFSP team writes that AT should be used, then the child's school or agency handling the child's case is the funding resource—meaning that they are responsible for providing the device and/or service (unless it is written otherwise in the IEP or IFSP document). Some examples of funding resources include:

- The early intervention service provider
- Public schools, private schools, Head Start
- Title V (CSHCN) programs
- Medicaid
- Private health insurance (as durable medical equipment, or DME)
- Disability organizations (Easter Seals, United Cerebral Palsy Association, March of Dimes, Braille Institute)
- Service organizations (Lions Club, Masonic order, Elks Club, United Way, Rotary Club, Kiwanis Club, Veterans of Foreign Wars [VFW]–children of veterans may receive assistance)
- Private organizations (PTA, special ed parent organizations, private industry)
- Self-pay

Human resources

Human resources include people who can perform AT assessments, trainings, and customizations. They include:

- School district AT specialist
- Hospital rehabilitation engineer
- Occupational, physical, and speech therapists who specialize in AT
- Cooperative Service Directory (CSD) listing of AT service providers as posted by the State Tech Act organizations of each state; for more information, check out the Trace Center at the University of Wisconsin-Madison Web site: http://trace.wisc.edu/tcel. ■

Adapted from the curriculum developed by the Childrens Hospital Los Angeles USC University Affiliated Program. The curriculum has been used to train parents and professionals about issues regarding assistive technology for infants and young children.

Sonia K. Aller, PhD, CCC is the Project Director of Tech for Tots™ and Toni Solano, MBA is the Project Manager.

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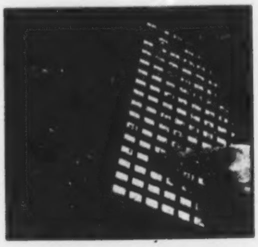

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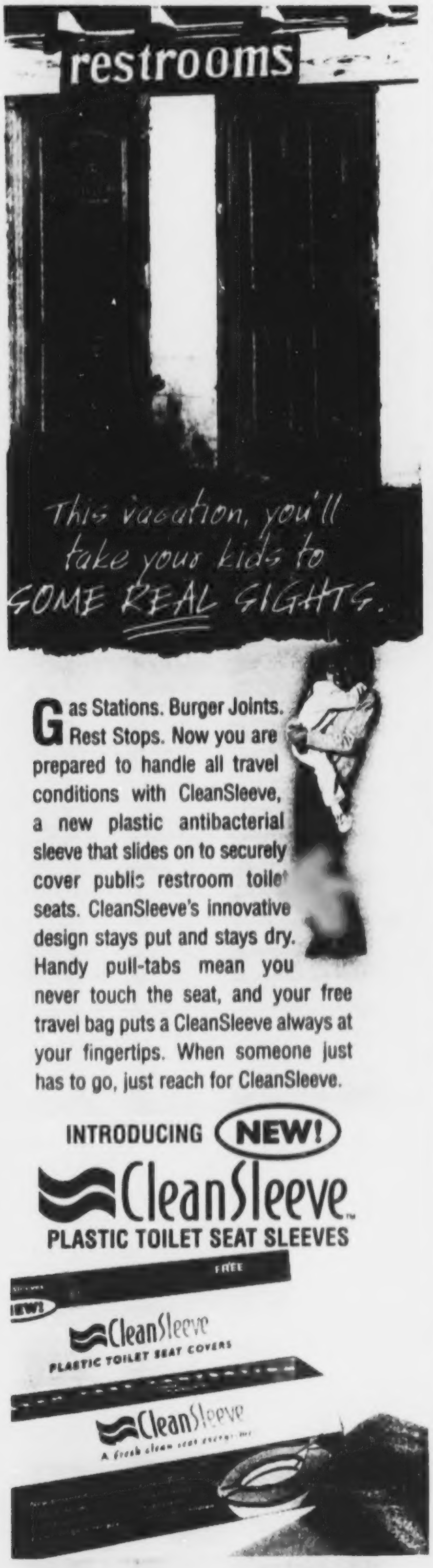
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organizational spotlight

Easter Seals

Creating Solutions, Changing Lives

Who are we?

For more than 81 years, Easter Seals, a nationwide, nonprofit organization established to help children and adults with disabilities live more independent lives, has been putting hope within reach for millions of people with disabilities by helping them develop the skills they need to live with dignity, equality and independence. Founded in 1919 by businessman Edgar Allen, Easter Seals was one of the first organizations established solely to help people with disabilities. Easter Seals now operates more than 400 service sites across the United States (including the District of Columbia and Puerto Rico), featuring many affordable services for children and adults with disabilities, their families and caregivers. All Easter Seals locations offer scholarships and sliding-scale fees for services. Fees vary from location to location.

Services

Helping a child without verbal skills communicate with his father; teaching a stroke victim skills to rejoin the work force; showing a child in a wheelchair he can still play sports with his friends; and providing a "night off" for parents of a child with cerebral palsy are just a few of the ways we serve our members. Everyday, Easter Seals creates solutions that change the lives of people with disabilities and their families by offering services that are comprehensive and individualized to meet each client's needs, family-focused to meet each family member's concerns, outcome-oriented with a goal of enhanced independence, and cost-effective, benefiting from public support. Our services include:

- **Children's Services** – To enhance development of children by providing them with a range of educational and health opportunities designed to help them reach their full potential.
- **Early Intervention Programs** – Designed to address the special needs of young children—from birth to 36 months—with existing or impending developmental disabilities to help them adapt and succeed in school and everyday life.
- **Child Development Centers** – High-quality, affordable, developmentally appropriate care in a safe and nurturing environment where children of all abilities can learn with their peers and hone new skills.
- **Camping and Recreation** – Easter Seals camps offer children and adults with disabilities the opportunity to experience the joys of summer camp without being held back by their limitations. Participating in activities ranging from canoeing and fishing to wheelchair tennis and rugby, Easter

Easter Seals exists to improve the quality of life for children and adults with disabilities and their families.

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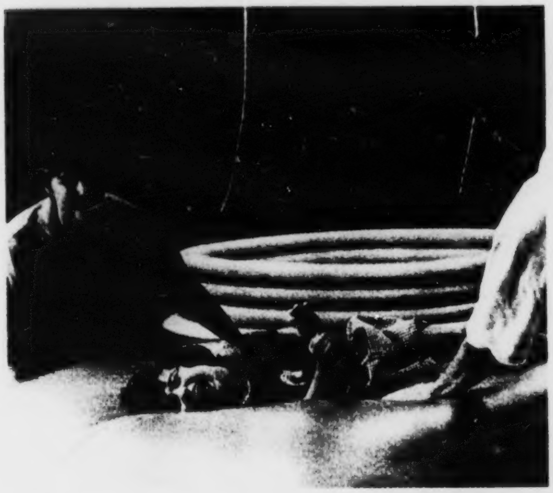
Seals campers can realize their potential in a safe and accessible environment.

- **Physical Medicine and Rehabilitation** – One of the largest networks for medical rehabilitation services. Easter Seals focuses primarily on the prevention, diagnosis and treatment of disabilities to help individuals live with greater independence. Rehabilitation services include: physical, occupational and recreational therapy, speech-language and audiology services, nursing and social work.
- **Job Training and Employment Services** – Provide individualized assistance to adults with disabilities seeking to join or rejoin the workforce. Easter Seals offers evaluation and assessment of occupational skills, job training and placement, and school-to-work transition programs for people with physical, mental and emotional disabilities.



Easter Seals uses dynamic therapy methods to help its members.

- **Respite Services** – Recognizing that caring for a loved one with a disability can be an overwhelming responsibility wrought with personal sacrifice, Easter Seals offers parents/caregivers a chance to take a night off from their duties and focus on themselves. Parents/caregivers of children with disabilities can leave their loved ones in the capable hands of Easter Seals staff overnight and enjoy time away to relax and recharge without worry.
- **Support Services** – We offer an array of services to help children and adults with disabilities and their families cope with the emotional strain associated with their disability. The support system coordinates and provides educational services, group meetings and information

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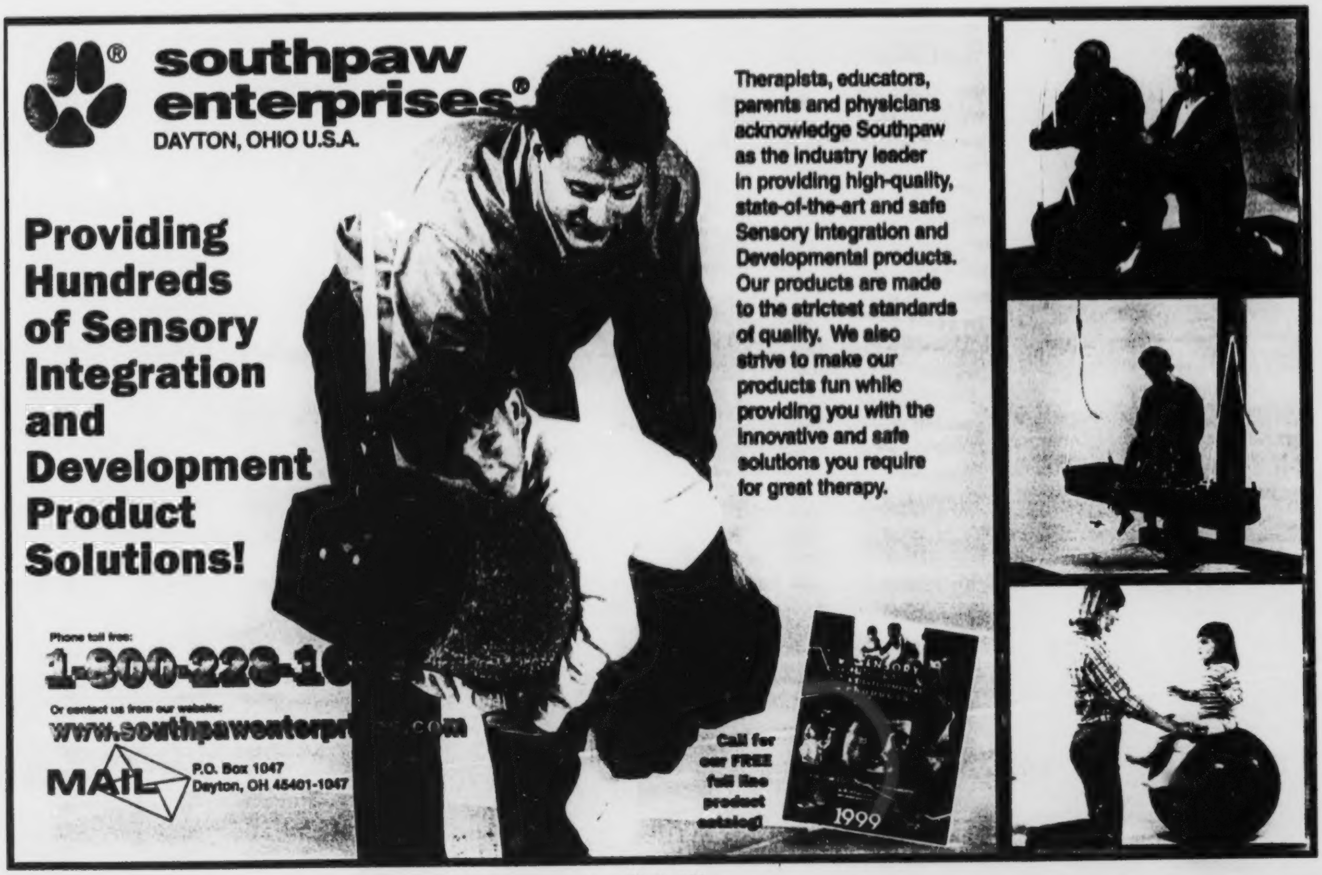

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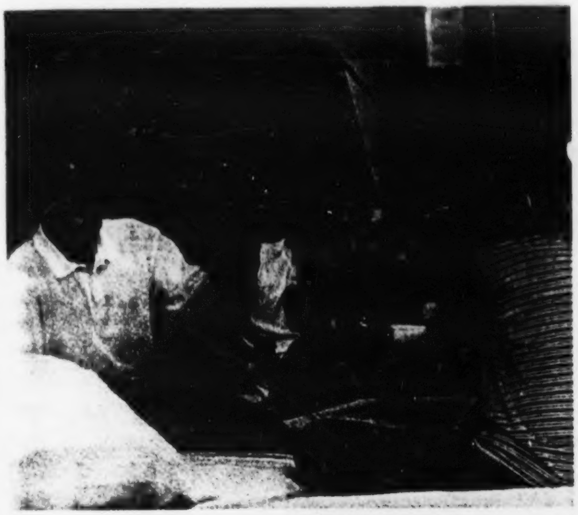
and referral services. Comprehensive care is often coordinated with other community service providers to address participants' ongoing needs.

Advocacy

Easter Seals exists to improve the quality of life of children and adults with disabilities and their families. Accomplishing this end requires both helping people with disabilities adapt to the world around them, and helping government and local communities adapt the world to accommodate their special needs.

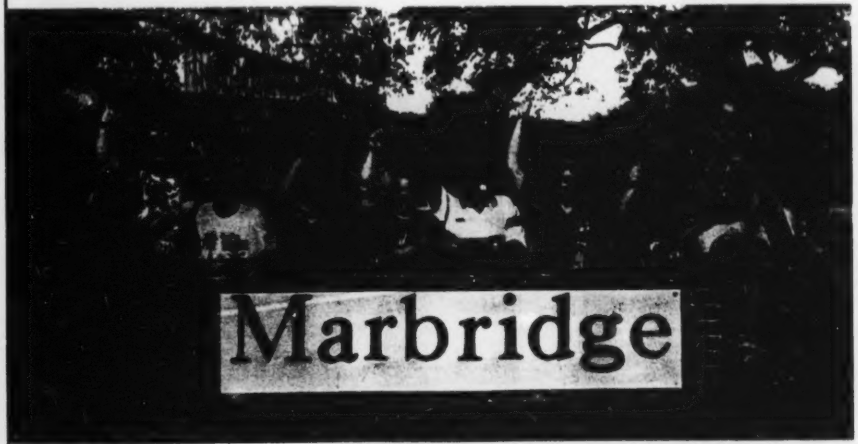
A leading advocate for the rights of people with disabilities, Easter Seals has long been active in the development and support of legislation and policy benefiting children and adults with disabilities and their families.



Physical therapy is just a part of the broad spectrum of services offered to Easter Seals members.

Landmark legislation realized with Easter Seals assistance includes:

- **Americans with Disabilities Act (ADA)** – Ten years ago, Easter Seals played a vital role in working with Congress to enact the ADA on July 26, 1990, which prohibits discrimination against people with disabilities in employment, access to state and local government services, public accommodations, transportation and telecommunications. Today, Easter Seals continues to work with people with disabilities, businesses, government agencies and the public to promote awareness and acceptance of the law.
- **Individuals with Disabilities Education Act (IDEA)** – For decades, Easter Seals has advocated for public policy that protects and



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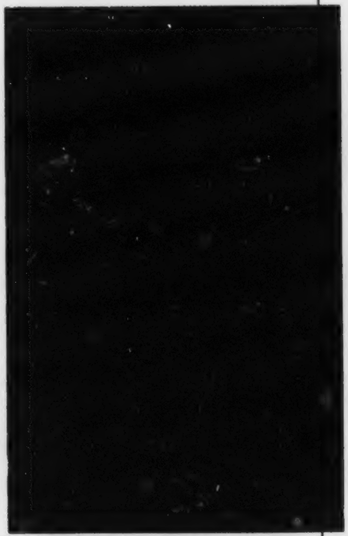
enhances the ability of students with disabilities to receive a free, appropriate public education that is tailored to meet individual needs. Since the enactment of IDEA in 1975, which guarantees just that, Easter Seals has been working aggressively with schools across the country to implement the law. The organization also continues to provide services that are financed by IDEA, including early intervention and preschool.

- **H.R. 1180 Ticket to Work and Work Incentives Improvement Act** – Less than half of one percent of Americans receiving disability benefits returns to work for fear of losing healthcare coverage upon reentering the workforce. On December 17, 1999, President Clinton made a major move to improve this untenable situation by signing H.R. 1180, which gives adults receiving disability benefits access to Medicaid and Medicare coverage after returning to work. This legislation also improves and expands vocational rehabilitation and employment service options and offers a system for reimbursing providers who help individuals enter the workforce. Easter Seals not only supported the enactment of this legislation, but will monitor its effectiveness to determine if established incentives are enough to increase the number of adults with disabilities returning to work. ■

Easter Seals not only supported the enactment of this legislation, but will monitor its effectiveness to determine if established incentives are enough to increase the number of adults with disabilities returning to work.

For more information on Easter Seals or to find an Easter Seals service site near you visit Easter Seals Web Site at www.easterseals.org or call (800) 221-6827.

Seeing Beyond the Disability



Palmer Harston (right): Easter Seals 2000 National Youth Representative

In April 1995, while on vacation, Palmer Harston, her sister Taylor, and her mother Julie were in a serious car accident. Taylor and Julie were both seriously injured, and Palmer suffered a traumatic spinal cord injury. As a result, Palmer's legs are paralyzed. Reeling from the traumatic reality of the accident and seeking the best possible care for their child, Palmer's family turned to Easter Seals. After a month in a trauma unit, the Harstons were transferred to Easter Seals Cardinal Hill Rehabilitation Hospital near their home in Lexington, Kentucky.

At Cardinal Hill, Palmer spent about six months in a body cast, and then received physical and occupational therapy. She learned how to use a wheelchair and how to perform everyday skills such as dressing herself and doing routine household chores. She took part in peer counseling sessions and visited with wheelchair athletes. Easter Seals Cardinal Hill even hosted an Easter Egg Hunt so her school classmates could visit with her.

While she was still in the trauma unit, Palmer's mother Julie made sure that Palmer had visits from family, friends, and fellow church members from home. "From the very beginning she had a lot of positive people around her, and this affected how she viewed her future."

As a parent, Julie feels that one of the hardest things for her was learning to let Palmer do things for herself. "When your child is seriously injured, you want to help them, and do things for them. It was hard not to baby her."

After four weeks of therapy, Palmer was able to return home. Julie says, "After such prolonged immobility, it was important to get her back into her usual activities, even if she did them in a different way." She knew it was crucial for her daughter to participate in the activities she had always done before.

Part of getting Palmer active again was giving her access to her home and school. The entire community got together and helped build ramps and a patio at the Harston home, and Julie campaigned to get a lift installed at the middle school. Palmer was able to return to her normal routine and become involved in all aspects of her life.

Palmer acknowledges that "Easter Seals helped put my life back together at a time when I didn't think that was possible." Easter Seals helped Palmer find a sports wheelchair and an adapted bike. Today, Palmer is an active 13-year-old and sings in her school choir, takes modeling classes, and enjoys riding her adapted bike, playing tennis, bowling, and gymnastics.

Palmer's family is optimistic about her future. "She has found that there are very few doors that are closed to her," says Julie. Both she and her husband, Buddy, are proud of what their daughter has accomplished.

Easter Seals offered Palmer the services she needed to get her life back on track and recognize the world of opportunity still open to her. As Easter Seals 2000 National Youth Representative, Palmer will be spending the year speaking to groups throughout the country. Palmer says she believes that people should see beyond the disability and focus on the person. Her advice? "Keep a positive outlook on life, and never take anything you have for granted."

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MEDICAL RESEARCH UPDATE

BY DAVID CHAMALIAN

SEDATION FOR CHILDREN NO LONGER NECESSARY WITH NEW, ULTRAFAST CT TECHNOLOGY

In order to keep children still during a computed tomography (CT) scan, sedation is often necessary. (A CT scan is a method of taking pictures of the inside of the body using an ultra-thin x-ray beam. The patient must remain as motionless as possible to ensure the quality of the scan image.) The use of anesthesia, however, carries the risk of sometimes dangerous side effects as well as associated costs and time needed for admission, examinations, and monitoring during and after the procedure. Newer, faster CT technology, which can complete a chest scan in 400 milliseconds, is now available (check with your local radiological center) to greatly diminish, or even eliminate the need for sedation so children can be imaged and discharged immediately.

In a study done on sixteen children, ranging in age from 3 weeks to 6 years, at the Walter Reed Army Medical Center in Bethesda, Maryland, John Statler, MD, and colleagues performed scans of the head, chest, neck, and abdomen and pelvis. According to three reviewing radiologists, all sixteen of the scans were of adequate diagnostic quality, and none needed repeating. Says Dr. Statler, "With this equipment, we should be able to start scanning the majority of pediatric patients with less or with no sedation."

EYE DISORDER AND ADHD: A POSSIBLE LINK

According to two separate studies, there is a "high occurrence" of convergence insufficiency (CI), a vision disorder that causes the eyes to move outward, among children with attention-deficit/hyperactivity disorder (ADHD). This latest finding indicates a potential link and has led the American Optometric Association (AOA) to advise parents that since most pre-school and school vision screenings are not designed to detect CI, they should be watchful of the disorder in their children, especially if other learning disabilities are present. AOA member Julie Ryan, OD, explains that a child's attempts to compensate for the outward movement of the eyes caused by CI can result in eye fatigue, headaches, and double vision, as greater effort is expended to keep the eyes aligned and focused. As a result, development and learning may be affected. Harvey P. Hanlen, OD, president of the AOA, recommends testing for the disorder if parents suspect that it exists in their child. "The standard of care for a pediatric eye examination by a doctor of optometry includes tests for CI, which can often be diagnosed in the pre-school years. Parents should be aware of this vision disorder since CI may make reading and learning more difficult. The earlier the problem is diagnosed, the sooner it can be corrected." Check the AOA Web site for more information on these studies: http://www.aoanet.org.

RARE DISORDERS UPDATE: SPINAL MUSCULAR ATROPHY (SMA)

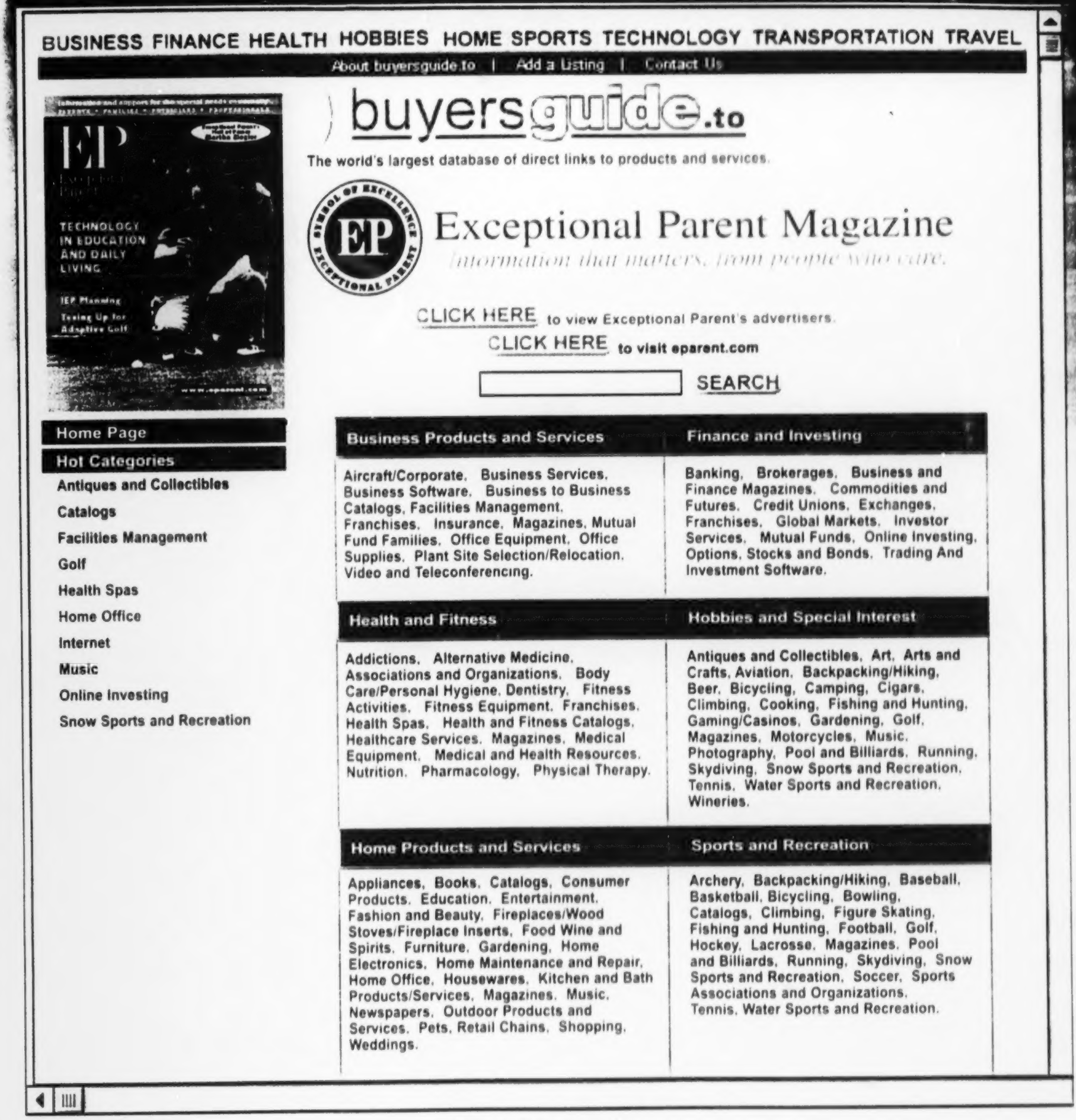
New treatments for SMA—sometimes called Kugelberg-Welander syndrome—are currently under study thanks to some promising research. Research shows that people with SMA lack the SMN1 gene, one of the two genes that produce vital proteins for the body. The absence of this gene creates a protein deficiency that is responsible for the onset of SMA, which destroys the nerve cells that control voluntary muscle movement, head and neck movement, crawling, walking, and often, swallowing. The latest research indicates that if a compound can be found to "trick" the SMN2 gene, the other protein-producing gene, into producing enough protein to compensate for the absence of SMN1, the effects of SMA could be decreased or even reversed. The search for that compound is already under way. According to Arthur Burghes, PhD, lead investigator in the study, "These findings demonstrate that someday we may be able to prevent this devastating disease." This study can be found in *Human Molecular Genetics*, February 2000.

INJECTION OF INSULIN-PRODUCING PANCREAS CELLS MAY WARD OFF TYPE 1 DIABETES

In a recent clinical trial in Canada, seven people with Type 1 diabetes have gone from two to fourteen months without their normal insulin shots, thanks to a new technique. (Also called juvenile diabetes, Type 1 diabetes requires those who have it to periodically inject insulin because their body's immune system kills the natural insulin secreted by the pancreas.) Researchers said that each of the study participants, ranging in ages from 29 to 54, had had diabetes for many years and a history of volatile metabolism and comas from very low blood sugar. Participants were also given immunosuppressants to prevent rejection of the transplanted cells.

Called "cell transplantation," the new technique involves inserting cells from an organ donor pancreas through an abdominal catheter and into the liver via the portal vein. The procedure requires only two 20-minute visits to administer the required amount of insulin-secreting cells. The Juvenile Diabetes Foundation calls the research "a very significant step forward in curing Type 1 diabetes," and, along with the National Institutes of Health (NIH), will provide financial backing for broader trials across North America and Europe.

Despite the promising news, however, researchers are cautious in their enthusiasm and are closely monitoring the long-term effects. The NIH Diabetes Transplant Chief, David Harlan, MD, states, "We have to understand we don't know a lot yet." To read the study, log onto the *New England Journal of Medicine* Web site: http://www.nejm.com.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PARENTS PLEASE NOTE: With sensitivity to any young readers you may have in your home, the following contains a frank discussion of sexuality. You may wish to exercise discretion.

Growing Pains

One family deals with the realities of puberty

by Vicki Pieser

I felt like a television mother out of the 1950s. The only thing missing was the shirt waist dress and a crinoline.

"Your son had an adult magazine magazine in his underwear drawer," I tattled to my husband.

"Where did he get that?"

"From your office."

"It must be twenty-five years old," he exclaimed, remembering what he thought was a valuable vintage collection from his college days.

"Josh doesn't care." And he certainly did not mind that those women with their pageboys were now grandmothers.

We both beamed proudly. How could this kid with a 55 IQ know to swipe girly magazines and hide them in his underwear drawer?

Vicki Pieser, righ
son,

TOMMY HILFIGER
JEANS

Puberty comes along

Teething and puberty were parenting myths, according to our past experiences. Teething for Joshua, we thought, was the excessive drooling he experienced while still toothless. When he was still drooling years later, we realized he never did teethe but the drooling that continues to plague him probably resulted from a brain injury.

He did go through puberty, though. When that burst of hormones shot though his sisters, they had the Sunday night blues, a condition that we viewed as a curse inherited from my side of the family. They would get a little misty-eyed when they had to face going back to school on Monday. As the next weekend came into view, the world looked better. If puberty itself was tumultuous for them, they both played their roles as good daughters very well. They kept teenage angst to themselves, adjusting to bras, cramps, new school, and the hormonal meteor shower they faced daily. In retrospect, they protected us from the angst of

continued on page 90

When we first adopted him, I had listened to the advice of a mother of eight and lay with him, skin to skin, mother to baby, teaching him to want to feel the skin and warmth of another person.

Charles C Thomas

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Circle #22

continued from page 88

their puberty in deference to the stresses we faced in dealing with their younger brother, who has developmental delay and autism.

Puberty hits

As a teenage boy, Joshua's anxieties lay elsewhere. He had always had an eye for attractive girls or women. He had preferred blondes since he was very small, but he always headed to pretty, flirtatious, charming women.

I did not know what to expect. When he was very young, we knew when he was in love with a teacher or a sitter or even a picture book. What would happen as he matured?

When he was 13 and told us, "My penis is looking up at me," we could no longer deny that puberty was real. Of course, the other physical signs had appeared. He did not seem to notice the pubic hair or the scattering of pimples on his face. His voice changed during a one-week camp session. When the staff let him call us to relieve his homesickness, he croaked, "Mom, come get me right now," sounding like a 70-year-old woman who had smoked for fifty years.

How could we deal with the adult magazine controversy? Yes, it was normal that he wanted to look at attractive women, but, we decided, it had to be in an appropriate and private place, like his room. We also had to monitor the time so that his obsessive tendencies did not turn this into the only interest in his life. That meant limiting the number of magazines in his possession. We knew only too well that when Josh loved something, he wanted as many of it as possible, whether that passion was for toy cars, balls, worms, or girly magazines.

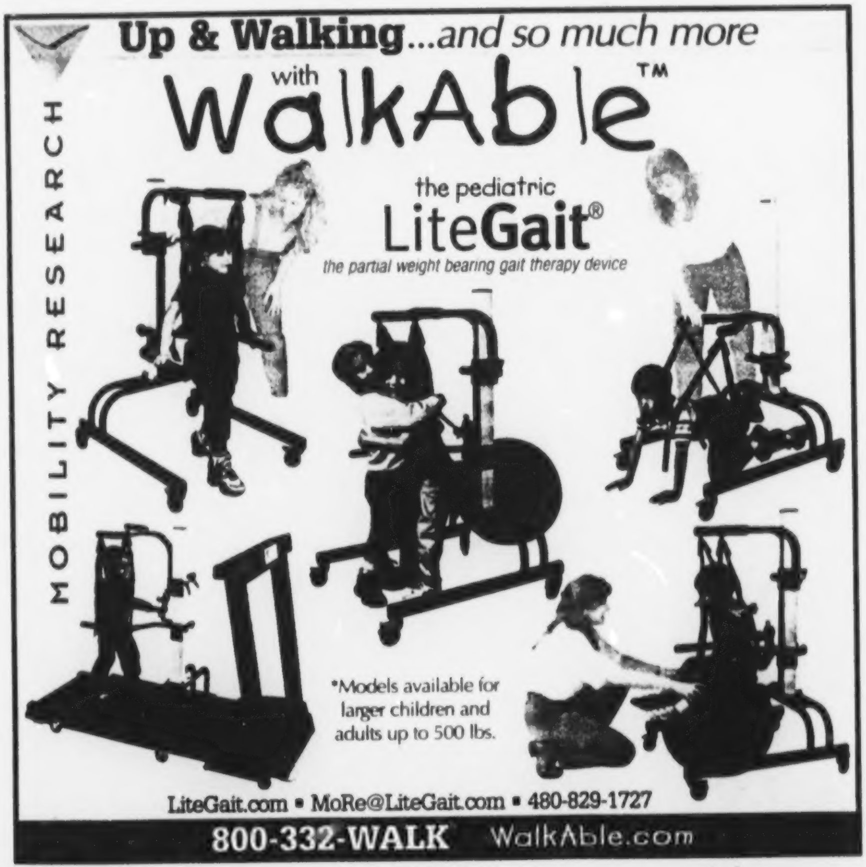
> **How could we have set him up for pain and rejection because we wanted to hold and love him? We felt that we had prepared him for a frustrating puberty and unfulfilled adult life.**

Dealing with changes

Fortunately, we did not have to forbid the purchase of more magazines that featured scantily clad women. On trips to bookstores following the discovery of the contraband magazines, I worried that the owner would be scowling at this mother buying soft-core pornography for her son. To my surprise, I followed him to the racks, where he reached for their large bridal section. His eye for beauty took precedence over lust. The magazines were not the most difficult aspect of puberty—love was.

With sadness, I remembered how we had worked to sensitize him to touch and affection. When we first adopted him, I had listened to the advice of a mother of eight and lay with him, skin to skin, mother to baby, teaching him to want to feel the skin and warmth of another person. We had considered his delayed acceptance of hugging and cuddling as a victory. I was angry at myself. What had I prepared him for if physical affection would be impossible for him, if it became a threat to others? Why didn't someone warn me that we were teaching him to want the touch of others, but that it would be withheld from him? How could we have set him up for pain and rejection because we wanted to hold and love him? We felt that we had prepared him for a frustrating puberty and unfulfilled adult life.

The first week of junior high, he talked about another seventh grader whose locker was near his. The crush progressed as unrequited love does. He talked incessantly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How could we have set him up for pain and rejection because we wanted to hold and love him? We felt that we had prepared him for a frustrating puberty and unfulfilled adult life.

about her at home. Could we have her over to play, he wondered? Or could she babysit him? He knew what kind of car her family drove, where she lived, what sport she played, the names of her siblings, but he did not know how to get closer to her.

Letting nature take its course

This interest—this obsession—worried us. We feared that he would embarrass himself at school, by revealing his secret crush to someone who might tease him. We worried that he would frighten her, that he would behave inappropriately to her or say something that would offend her.

The year passed without incident. We warned his teacher about his feelings, so this very experienced and wise man could monitor and advise us. His reports back to us were favorable. Joshua knew what the boundaries were or he sensed how to act in public. He never behaved suspiciously at school. He was discreet. He never even spoke to the girl. The challenge of a relationship was overwhelming, and he was shy.

For us, his brush with love was poignant. Few 14-year-old boys or girls live through their first or second or successive crushes with no pain or embarrassment. Few are smooth enough, attractive enough, or poised enough to choose that special other, communicate those feelings, and consummate the relationship even in the naming of it...the boyfriend, the girlfriend. Other people can claim and treasure that first love as a part of their history, remembered for bittersweet memories and well-learned lessons.

For Joshua, there were no furtive glances, no hand-holding between classes, no messages carried by friends at lunch. It was a shadow of a love relationship. Gradually, he quit asking to drive by her house and to invite her over. He carried her picture around with him and in his mind, she was his. ■

Vicki Pieser and her husband, Ben, are the parents of three children and grandparents of one. The family lives in Minnesota.

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DEAN

Dean Christopher Johnson, 3, gets hugs from mom, **Traci**, and dad, **Chris**. Dean suffered a traumatic brain injury last year when he was hit by a car. He is unable to walk, talk, or do most of the things he used to do. He loves music and his favorite songs are "The Wheels on the Bus" and "If You're Happy and You Know It." He also likes painting with his school teacher and playing with his toys. Dean and his parents live in Hutchinson, MN.

SHANTEL

Shantel Sims, 8, loves her baby brother, **Hunter**, 9 months! Shantel was born with chromosome 10 deletion (a rare disorder that can result in varying levels of disability). She is fully included with aides in her second grade class at Landolt Elementary School. Shantel enjoys ballet and has been in several performances. She also loves gardening, flowers, ladybugs, and most of all, being a big sister! Shantel lives with Hunter and her mom, Dawn, and dad, Rodney, in Friendswood, TX.

SHANNON

Shannon Doyle, 4, is the queen of her castle! Shannon has cerebral palsy and has just gotten a motorized wheelchair, which she really enjoys. Shannon loves her preschool and being with the other children. She also enjoys playing with her Barbies® and her toy garage, and eating macaroni & cheese! Her mom, Judi, says Shannon smiles all the time, and that nothing stops her. Shannon lives with her mom and dad, William, in Everett, MA.

Would you like to share a favorite candid snapshot or slide of your child and/or family with other readers of EXCEPTIONAL PARENT? Send it to: Readers' Photos, *EXCEPTIONAL PARENT*, 555 Kinderkamack Road, Oradell, NJ 07649-1517. (Please do not send originals or "one-of-a-kinds" as we regret that **photos cannot be**

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HALEY

Haley Brooke Sulahian, 2, and her big brother **Scott**, 14, horse around while having portraits taken. Haley has bilateral schizencephaly (a rare disorder characterized by abnormal clefts in the brain's cerebral hemispheres) and cerebral palsy. She receives physical, speech, and occupational therapy twice a week. Haley loves horseback riding, swimming, being read to, playing with her dolls, drawing, and being outdoors. She and her brother live in St. Augustine, FL, with their parents, Jill and Bill.

SPENCER

Spencer Avery Sapp, is ready for fun! Spencer was 1-year old when this picture was taken, but will be 2 in August. He has cerebral palsy and currently receives occupational, physical, and speech therapy. He has also started receiving aquatherapy, which he loves. Spencer enjoys listening to songs, especially "Old MacDonald," going for walks, and playing with his two brothers, Aaron, 8, and Austin, 4, whom he adores. The three brothers live with their parents, Judy and Douglas, in Jeffersonville, IN.

NICHOLAS

Home on the range! **Nicholas Gilmore**, 4, is all smiles. Nicholas has Down syndrome and attends the Space Coast Early Intervention Center in Melbourne, FL, where he receives occupational and speech therapies. Nicholas loves going to the park, playing with his puppies, and watching videos about trains and trucks. He lives with his mom, Patricia, dad, Edward, and big brother, Anthony, 7, in Sebastian, FL.

returned.) On a separate sheet of paper, write your child's full name, age at the time the photo was taken, address and daytime phone number. Please identify everyone in the photo. If you like, you can also write a few sentences about your child. Then look for a familiar face in an upcoming issue!

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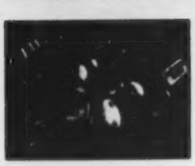

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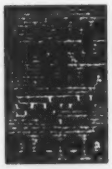

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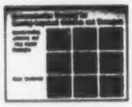

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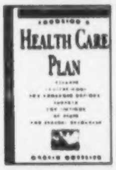

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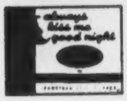

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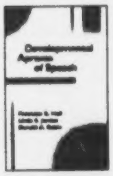

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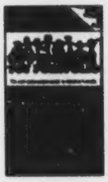

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LEGISLATIVE UPDATE

by David Chamalian

New autism legislation pending

Chris Smith (R-4), a congressman from New Jersey, is sponsoring legislation in Congress that if passed will provide funds to gather and compile national autism statistics. According to Carla Israel, family outreach coordinator of Mid-Jersey Cares for Special Children, a regional early intervention collaborative in New Jersey, knowing how many people have autism, who these people are, who is at risk for autism, and tracking diagnosis trends can facilitate the design of successful prevention strategies and, eventually, aid in finding a cure. Included in Representative Smith's research bill, The Autism Statistics Surveillance, Research, and Epidemiology Act—HR 274, are the following provisions:

- Over the next five years, $37,500,000 will be appropriated to the Centers for Disease Control and Prevention (CDC) to create the National Autism and Pervasive Developmental Disabilities Program, which will be charged with monitoring the prevalence of autism at the national level; assisting in the development of state autism surveillance programs; providing education and training for health professionals to improve treatments for autism; and developing expertise in one or more areas of autism research.
- An independent public and governmental advisory committee made up of government experts, parents and clinicians will report annually to Congress on the progress of the Program.
- The CDC will also become a national clearinghouse for autism research and policy.

To help this legislation pass, Ms. Israel recommends voters urge their state senator or House representative to sign on as bill cosponsors by contacting them and explaining the importance of having national statistics on autism. She also recommends attaching a picture of the person they know with autism to the letter.

EDITOR'S NOTE: Contact your state representatives and senators at the following Web sites: http://www.house.gov; http://www.senate.gov; or obtain more information by calling the Capitol switchboard: (202) 224-3121.

Government Web sites soon to be accessible to everyone

Legislation known as Section 508, which was signed into law by President Clinton in 1998, will require that all federal Web sites produced after August 7, 2000, be made accessible to people with disabilities, namely people with hearing or visual impairments. The thrust behind the law is the assurance that people with disabilities can gain access to the same electronically disseminated information that is available to the general public. Among the measures that will be implemented to make the sites accessible are text-reading technology for people with visual impairments and the placing of captions on audio material for people with hearing impairments. The law will apply to approximately 105 federal departments and agencies.

Commercial Web sites are not affected by the new law, although the former Chairman of a Section 508 advisory committee to the Access Board, Lawrence A. Scadden, believes that the new law may eventually spur more sweeping standards by reshaping user expectations when they log on to non-government sites. "These Web sites will become models for the private sector," he said.

House passes bill aimed at furthering research into children's disorders and diseases

In May of this year, the House of Representatives voted favorably (419-2) for approval of the Children's Health Act of 2000 (HR-4365), legislation that will authorize funding for research into a variety of children's diseases and disorders, including juvenile diabetes, juvenile arthritis, autism, fragile X syndrome, asthma, spina bifida, cerebral palsy, epilepsy, traumatic brain injury, early hearing loss, and various birth defects. Among the many provisions of the bill is the Pediatric Research Initiative, which seeks to "ensure expanded opportunities for advancement in scientific investigations and care for children" and develop "adequate pediatric clinical trials ... to promote the safer and more effective use of prescription drugs in the pediatric population." For further information on HR-4365, contact the Alliance for Children & Families' office of public policy by phone at (800) 220-1016; E-mail: policy@alliance1.org; or click on the "Thomas" link on the House of Representatives Web site: http://www.house.gov.

EDITOR'S NOTE: This bill is currently in Senate committee awaiting passage.

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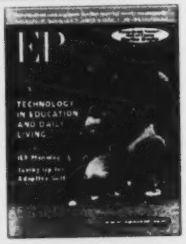

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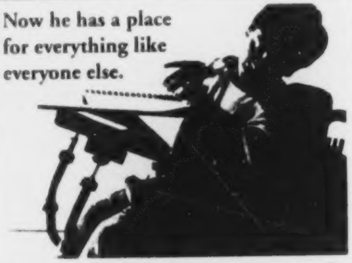

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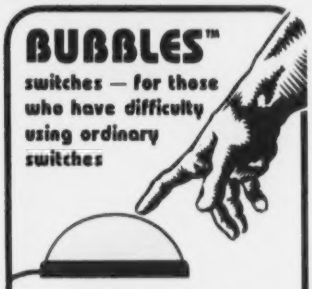

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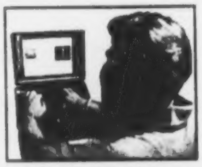
This training and reminder system is designed for children and adults with cognitive disabilities. The WatchMinder is a standard wristwatch with a silent vibration alarm system that can be programmed to train and/or remind the wearer throughout the day. It contains 75 pre-programmed messages and 16 daily alarms. When the alarm briefly vibrates, the user can see the relevant message on the large display. Messages address specific tasks, such as taking medication, doing homework and chores, as well as prompting behavior changes and self-monitoring. It comes with a belt clip and is small enough to carry in a pocket.

WatchMinder, PMB #278, 5405 Alton Pkwy #5A, Irvine, CA 92604-3718; Phone: (800) 961-0023; Fax: (949) 854-1843; Web site: http://www.watchminder.com; E-mail: addhelper@watchminder.com



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Interactive Solutions Inc., 2150 Whitfield Industrial Way, Sarasota, FL 34243-4046; Phone: (888) 463-0474, (800) 362-4584 (TDD); Fax: (941) 751-7777; Web site: http://www.teachthedeaf.com; E-mail: sales@teachthedeaf.com

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For more information on these and other assistive devices, or to submit product information for the database (and possible inclusion on this page), contact: **ABLEDATA, 8630 Fenton, Suite 930, Silver Springs, MD 20910; (800) 227-0216 or (301) 608-8998 (voice); (301) 608-8912 (TTY); (301) 608-8958 (fax); Web site: http://www.abledata.com.**

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Good Things Come in SMALL Packages

by Jessica Morgan

It is said that beauty is in the eye of the beholder. In Carolyn's eyes, everything is beautiful. She is always so happy that beauty seems to generate into the hearts of everyone around her.

Carolyn Dadd, 15, has moyamoya disease (see Editor's Note). She cannot walk, talk or feed herself, and she requires total care. She knows the people around her, though. I only wish more people could realize how capable she is.

I am 19-years-old, and I have been Carolyn's sitter for the past seven years. I first met Carolyn when I was 12 and she was 9. I had never seen anyone quite like her. She was very small then, barely 60 pounds. Her smile was deep as if it sank back into her soul. When we met she raised her hand in a gentle motion to touch my face and laughed as if there was a joke between us. Soon I found myself laughing, too. That day started our friendship—one that I will cherish the rest of my life. It was obvious that Carolyn was different from anyone I had ever met, and that is exactly what I liked about her.

Life-long buddies: Jessica (left) and Carolyn show the warmth of their friendship.

In the summer I turned 15, I was Carolyn's full-time caregiver. Since then I have learned much about her, like how she loves children. She likes to touch their faces, and her mom says that when Carolyn touches a face, it is her way of giving a hug. I have also learned all the tricks to make her laugh. For example, she loves when I slam the huge oak door in her play room, or when I push her backwards in her stroller. I love to hear her laugh, because it reminds me that life is good.

With the love I have felt for Carolyn I have also become very protective of her. When I see people stare at her I think it is very rude and narrow-minded. Just because Carolyn cannot ask, "Hey, what are you looking at?" does not mean she is not thinking it.

Carolyn has a light inside her that I have never seen in anyone else. She has a wonderful life, an amazing family and a whole community that knows and loves her. She has taken everything God has given her and used it to be the most wonderful little girl I have ever met, and she has influenced me to do the same.

I will always hold all the memories we have shared very close to my heart. Though I do not sit much for her anymore, I still see Carolyn every night when she comes to see me at Wayne's Ice Cream World, where I work. I have always got her favorite flavor, chocolate, waiting for her when she comes smiling in through the door. ■

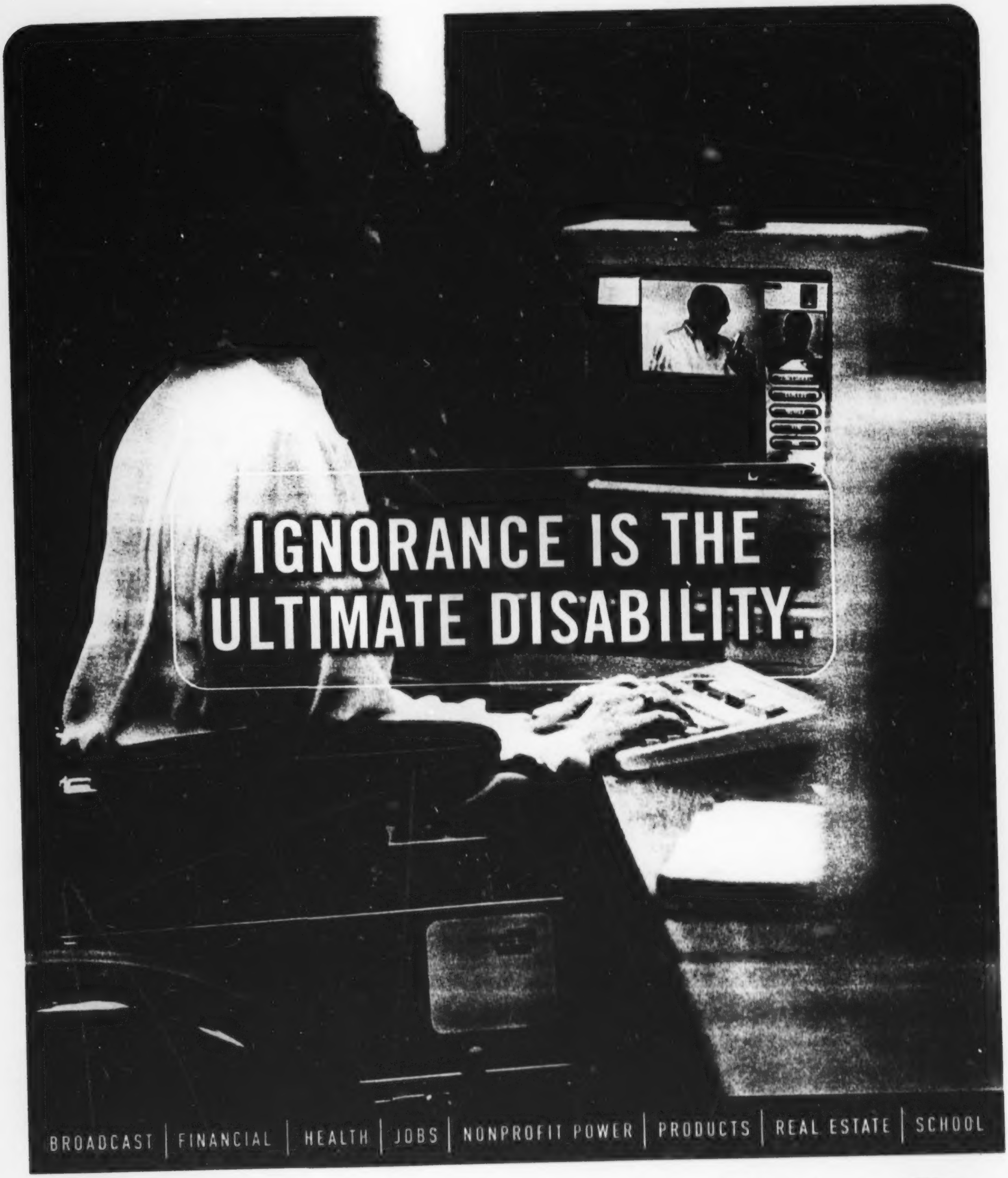
MOM'S TURN

According to Carolyn's mother, Margaret, Carolyn is very social and has plenty of moxie. When she wants something, she definitely lets her wishes be known. Jessica, meanwhile, has had a great impact on Carolyn. "What is great about Jessica is that she has treated Carolyn like one of her girlfriends."

Both Jessica and Carolyn live in Attica, NY.

EDITOR'S NOTE: Moyamoya disease is a progressive disease that affects the blood vessels in the brain. It is characterized by narrowing and/or closing of the carotid artery. This lack of blood may cause paralysis of the feet, legs or upper extremities. Headaches, various vision problems, mental retardation and psychiatric problems may also occur.

The Children's Page welcomes contributions from children who have disabilities, their siblings, and their friends. Be creative! Send your stories, photos and/or artwork to: Children's Page, EXCEPTIONAL PARENT, 555 Kinderkamack Road, Oradell, NJ 07649-1517. Be sure to include your name, address, and day-time telephone number! Now on the Web! We will now be including **Familiar Faces** and **Children's Page** on our Web site, www.eparent.com. Please send us your photographs with the understanding that doing so gives Exceptional Parent permission to put the photos on the Exceptional Parent Web site, exactly as they appear in the magazine and with the same text.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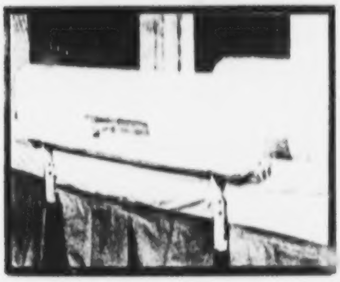

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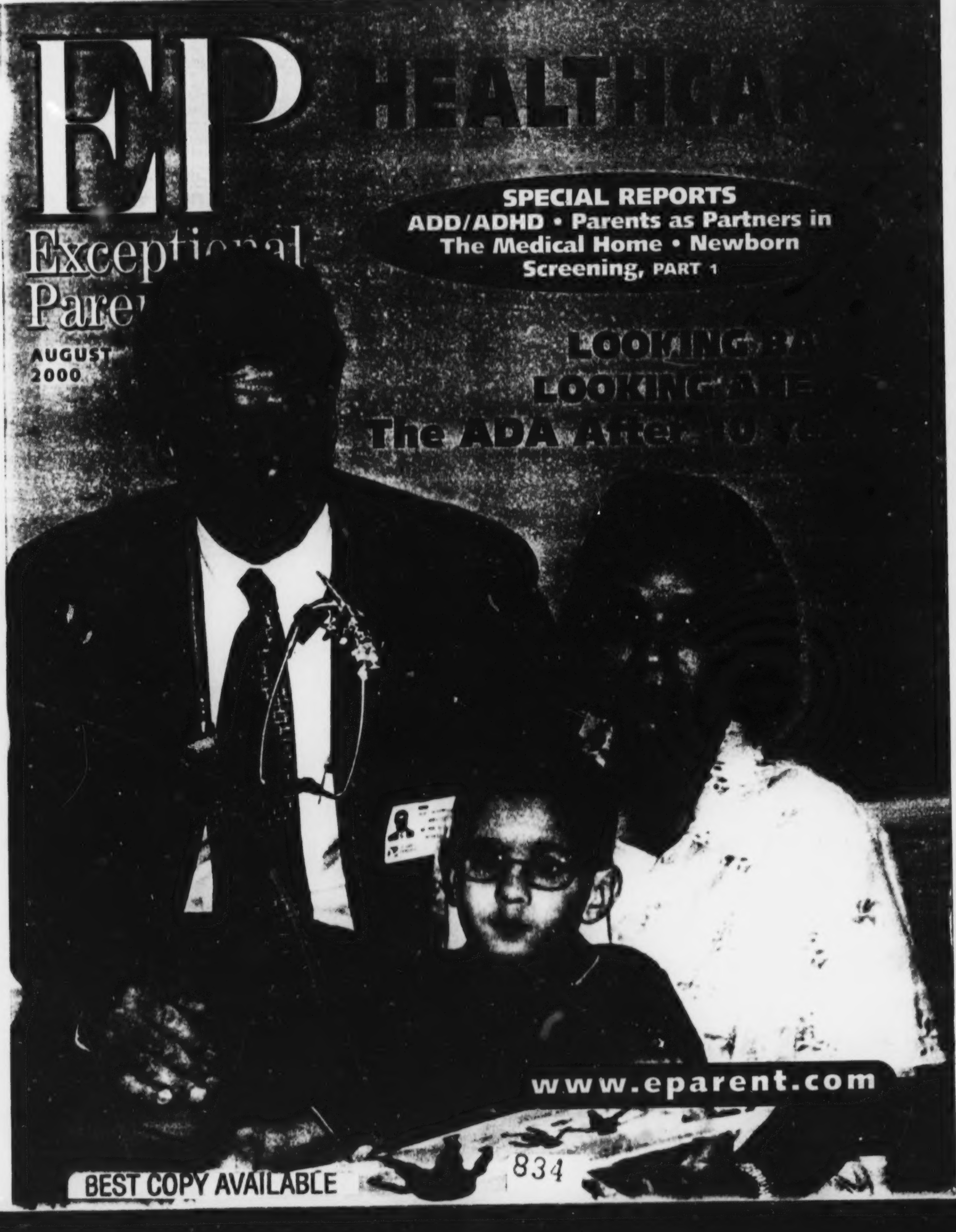

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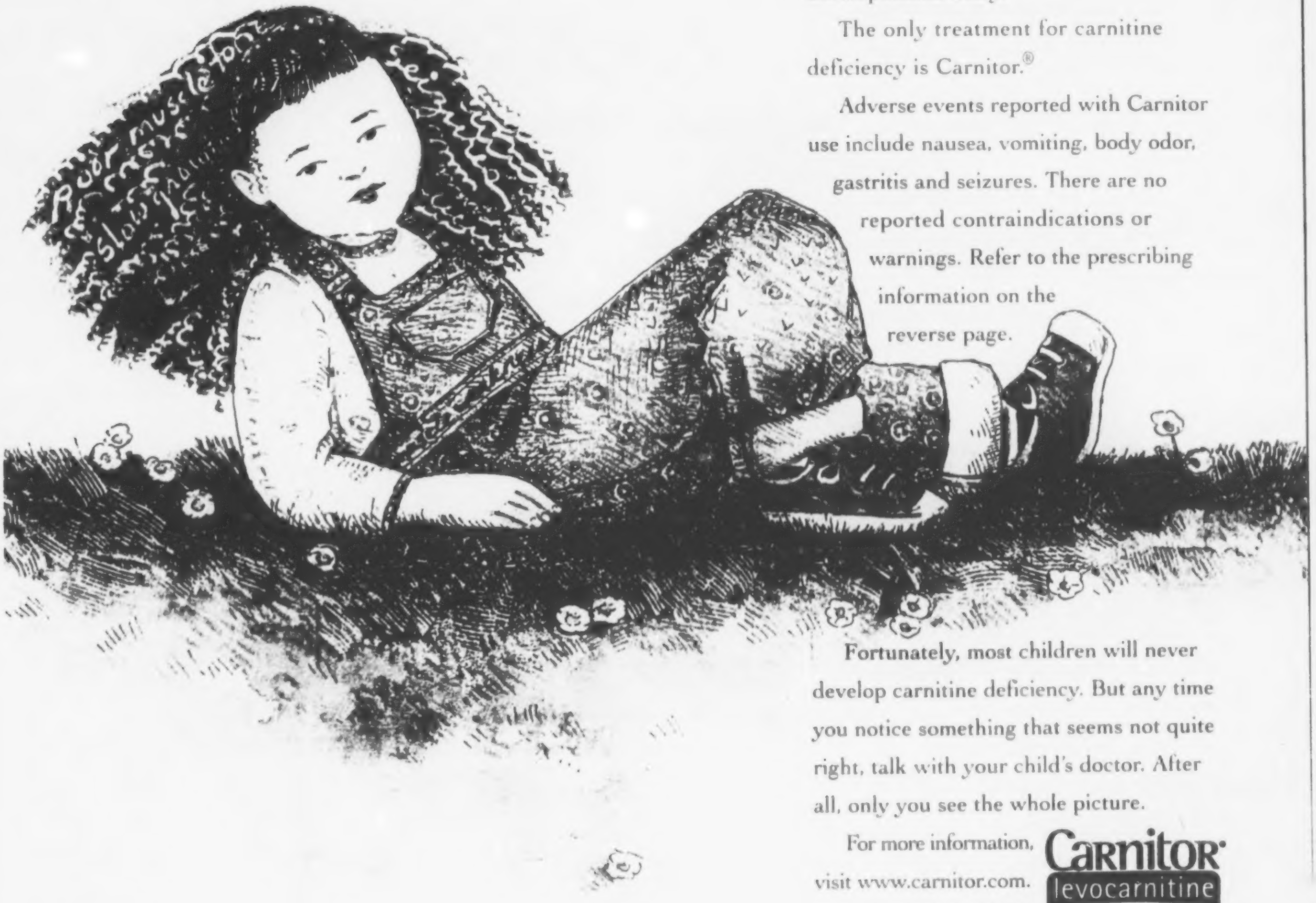

No one knows your child as well as you do. So no one's better at seeing the subtle things that affect your child's health. Things like carnitine deficiency.

Carnitine is a naturally occurring substance that's essential in the metabolic process. If the body is deficient in carnitine, the ability of the cells to produce energy and to remove toxic wastes is impaired. And while carnitine deficiency can be serious, its symptoms are hard to detect and are often overlooked.

Signs include muscle weakness, frequent infection, seizures, poor muscle tone, slow growth, speech difficulties, slow weight gain, lack of energy and developmental delay.

The only treatment for carnitine deficiency is Carnitor.®

Adverse events reported with Carnitor use include nausea, vomiting, body odor, gastritis and seizures. There are no reported contraindications or warnings. Refer to the prescribing information on the reverse page.

Fortunately, most children will never develop carnitine deficiency. But any time you notice something that seems not quite right, talk with your child's doctor. After all, only you see the whole picture.

For more information, visit www.carnitor.com. Or call 1-800-447-0169.

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BRIEF SUMMARY

The following is a brief summary. Please see package insert for full prescribing information.

CLINICAL PHARMACOLOGY

CARNITOR® (levocarnitine) is a naturally occurring substance required in mammalian energy metabolism. It has been shown to facilitate long-chain fatty acid entry into cellular mitochondria, therefore delivering substrate for oxidation and subsequent energy production. Fatty acids are utilized as an energy substrate in all tissues except the brain. In skeletal and cardiac muscle they serve as major fuel. Primary systemic carnitine deficiency is characterized by low plasma, RBC, and/or tissue levels. It has not been possible to determine which symptoms are due to carnitine deficiency and which are due to the underlying organic acidemia, as symptoms of both abnormalities may be expected to improve with carnitine. The literature reports that carnitine can promote the excretion of excess organic or fatty acids in patients with defects in fatty acid metabolism and/or specific organic acidopathies that bioaccumulate acyl CoA esters.

Secondary levocarnitine deficiency can be a consequence of inborn errors of metabolism. CARNITOR® may alleviate the metabolic abnormalities of patients with inborn errors that result in accumulation of toxic organic acids. Conditions for which this effect was demonstrated are: glutaric aciduria II, methyl malonic aciduria, propionic acidemia, and medium chain fatty acyl CoA dehydrogenase deficiency. Autointoxication occurs in these patients due to the accumulations of acyl CoA compounds that disrupt intermediary metabolism. The subsequent hydrolysis of the acyl CoA compound to its free acid results in acidosis that can be life threatening. Levocarnitine clears the acyl CoA compound by formation of acyl carnitine which is quickly excreted.

Levocarnitine deficiency is defined biochemically as abnormally low plasma levels of free carnitine, (less than 20 µmol/L at one week post term) and may be associated with low tissue and/or urine levels. Further, this condition may be associated with a ratio of plasma ester/free levocarnitine levels greater than 0.4 or abnormally elevated levels of esterified levocarnitine in the urine. In premature infants and newborns, secondary deficiency is defined as plasma free levocarnitine levels below age related normal levels.

BIOAVAILABILITY/PHARMACOKINETICS

In a relative bioavailability study in 15 healthy adult male volunteers CARNITOR® Tablets were found to be bio-equivalent to CARNITOR® Oral Solution. Following the administration of 1980 mg b.i.d., the maximum plasma concentration level (C_{max}) was 80 nmol/mL and the time to maximum concentration (T_{max}) occurred at 3.3 hours. There were no significant differences for AUC and urinary excretion observed between these two formulations.

In the same bioavailability study of 15 healthy adult males, CARNITOR® (levocarnitine) Injection administered as a slow 3 minute bolus intravenous injection at a dose of 20 mg/kg showed that free levocarnitine plasma profiles are best fit by a two compartment model. Approximately 76% of free levocarnitine is eliminated in the urine. Using plasma levels uncorrected for endogenous levocarnitine, the mean distribution half life was 0.585 hours and the mean apparent terminal elimination half life was 17.4 hours following a single intravenous dose.

The absolute bioavailability of L-carnitine from CARNITOR® Tablets and Oral Solution was determined compared to the bioavailability of L-carnitine from CARNITOR® Injection Intravenous in 15 healthy male volunteers. After correction for circulating endogenous levels of L-carnitine in the plasma, absolute bioavailability was 15.1% ± 5.3% for L-carnitine from CARNITOR® Tablets and 15.9% ± 4.9% from the Oral Solution.

Total body clearance of L-carnitine (Dose/AUC including endogenous baseline levels) was a mean of 4.00 L/hr. Endogenous baseline levels were not subtracted since total body clearance of L-carnitine does not distinguish between exogenous sources of L-carnitine and endogenously synthesized L-carnitine. Volume of distribution of the intravenously administered dose above baseline endogenous levels was calculated to be a mean of 29.0 L ± 7.1 L (approximately 0.39 L/kg) which is an underestimate of the true volume of distribution since plasma L-carnitine is known to equilibrate slowly with, for instance, muscle L-carnitine.

L-carnitine was not bound to plasma protein or albumin when tested at any concentration or with any species including the human.

INDICATIONS AND USAGE

CARNITOR® (levocarnitine) is indicated in the treatment of primary systemic carnitine deficiency. In the reported cases, the clinical presentation consisted of recurrent episodes of Reye-like encephalopathy, hypoketotic hypoglycemia, and/or cardiomyopathy. Associated symptoms included hypotonia, muscle weakness and failure to thrive. A diagnosis of primary carnitine deficiency requires that serum, red cell and/or tissue carnitine levels be low and that the patient does not have a primary defect in fatty acid or organic acid oxidation (see Clinical Pharmacology). In some patients, particularly those presenting with cardiomyopathy, carnitine supplementation rapidly alleviated signs and symptoms. Treatment should include, in addition to carnitine, supportive and other therapy as indicated by the condition of the patient.

CARNITOR® (levocarnitine) is also indicated for acute and chronic treatment of patients with an inborn error of metabolism that results in a secondary carnitine deficiency.

CONTRAINDICATIONS

None known.

WARNINGS

None.

PRECAUTIONS

General

CARNITOR® (levocarnitine) Oral Solution is for oral/internal use only.

Not for parenteral use.

Gastrointestinal reactions may result from too rapid consumption of carnitine. CARNITOR® (levocarnitine) Oral Solution may be consumed alone, or dissolved in drinks or other liquid foods to reduce taste fatigue. It should be consumed slowly and doses should be spaced evenly throughout the day to maximize tolerance.

Carcinogenesis, mutagenesis, impairment of fertility

Mutagenicity tests performed in *Salmonella typhimurium*, *Saccharomyces cerevisiae*, and *Schizosaccharomyces pombe* indicate that CARNITOR® (levocarnitine) is not mutagenic. Long-term animal studies have not been conducted to evaluate the carcinogenicity of the compound.

PREGNANCY

Pregnancy Category B.

Reproductive studies have been performed in rats and rabbits at doses up to 3.8 times the human dose on the basis of surface area and have revealed no evidence of impaired fertility or harm to the fetus due to CARNITOR®. There are, however, no adequate and well controlled studies in pregnant women. Because animal reproduction studies are not always predictive of human response, this drug should be used during pregnancy only if clearly needed.

NURSING MOTHERS

It is not known whether this drug is excreted in human milk. Because many drugs are excreted in human milk, a decision should be made whether to discontinue nursing or to discontinue the drug, taking into account the importance of the drug to the mother.

PEDIATRIC USE

See Dosage and Administration.

ADVERSE REACTIONS

Various mild gastrointestinal complaints have been reported during the long-term administration of oral L- or D,L-carnitine; these include transient nausea and vomiting, abdominal cramps, and diarrhea. Mild myasthenia has been described only in uremic patients receiving D,L-carnitine. Gastrointestinal adverse reactions with CARNITOR® (levocarnitine) Oral Solution dissolved in liquids might be avoided by a slow consumption of the solution or by a greater dilution. Decreasing the dosage often diminishes or eliminates drug-related patient body odor or gastrointestinal symptoms when present. Tolerance should be monitored very closely during the first week of administration, and after any dosage increases.

Seizures have been reported to occur in patients with or without pre-existing seizure activity receiving either oral or intravenous levocarnitine. In patients with pre-existing seizure activity, an increase in seizure frequency and/or severity has been reported.

OVERDOSAGE

There have been no reports of toxicity from carnitine overdosage. The oral LD_{50} of levocarnitine in mice is 19.2 g/kg. Carnitine may cause diarrhea. Overdosage should be treated with supportive care.

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Monitoring should include periodic blood chemistries, vital signs, plasma carnitine concentrations and overall clinical condition.

CARNITOR® (levocarnitine) Oral Solution.
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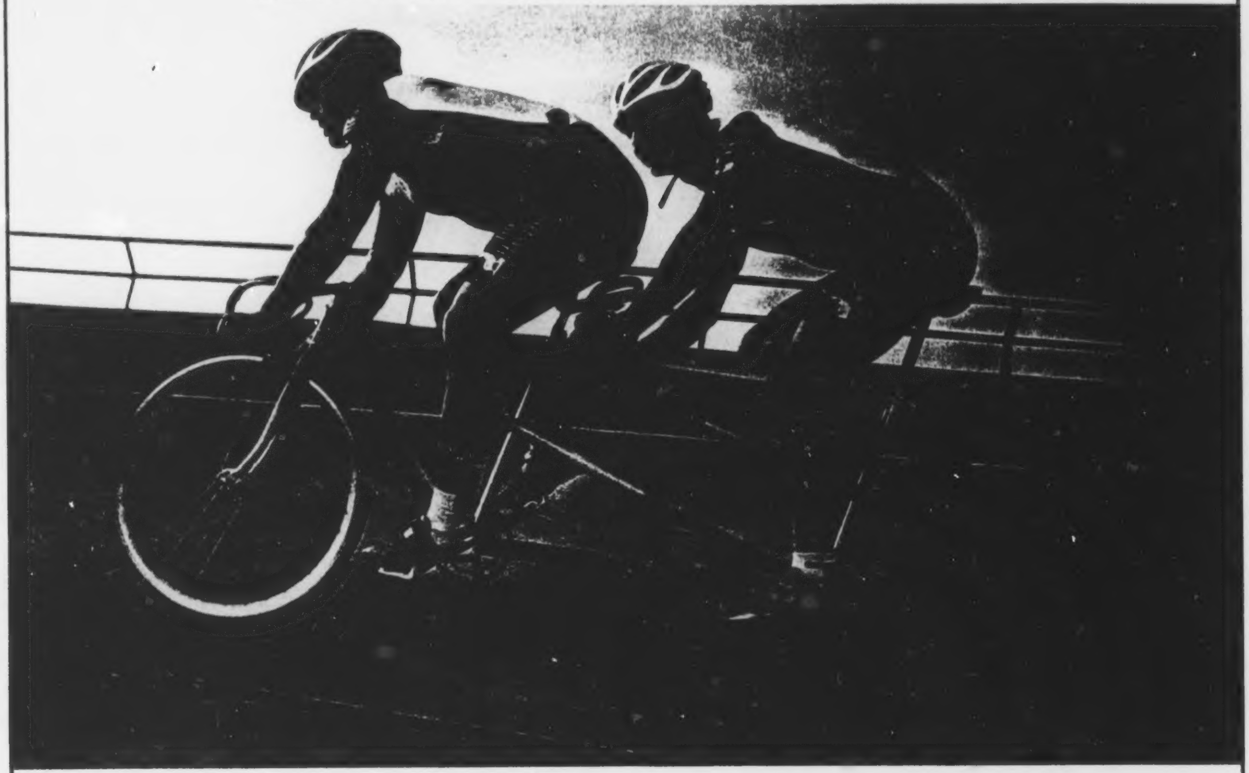

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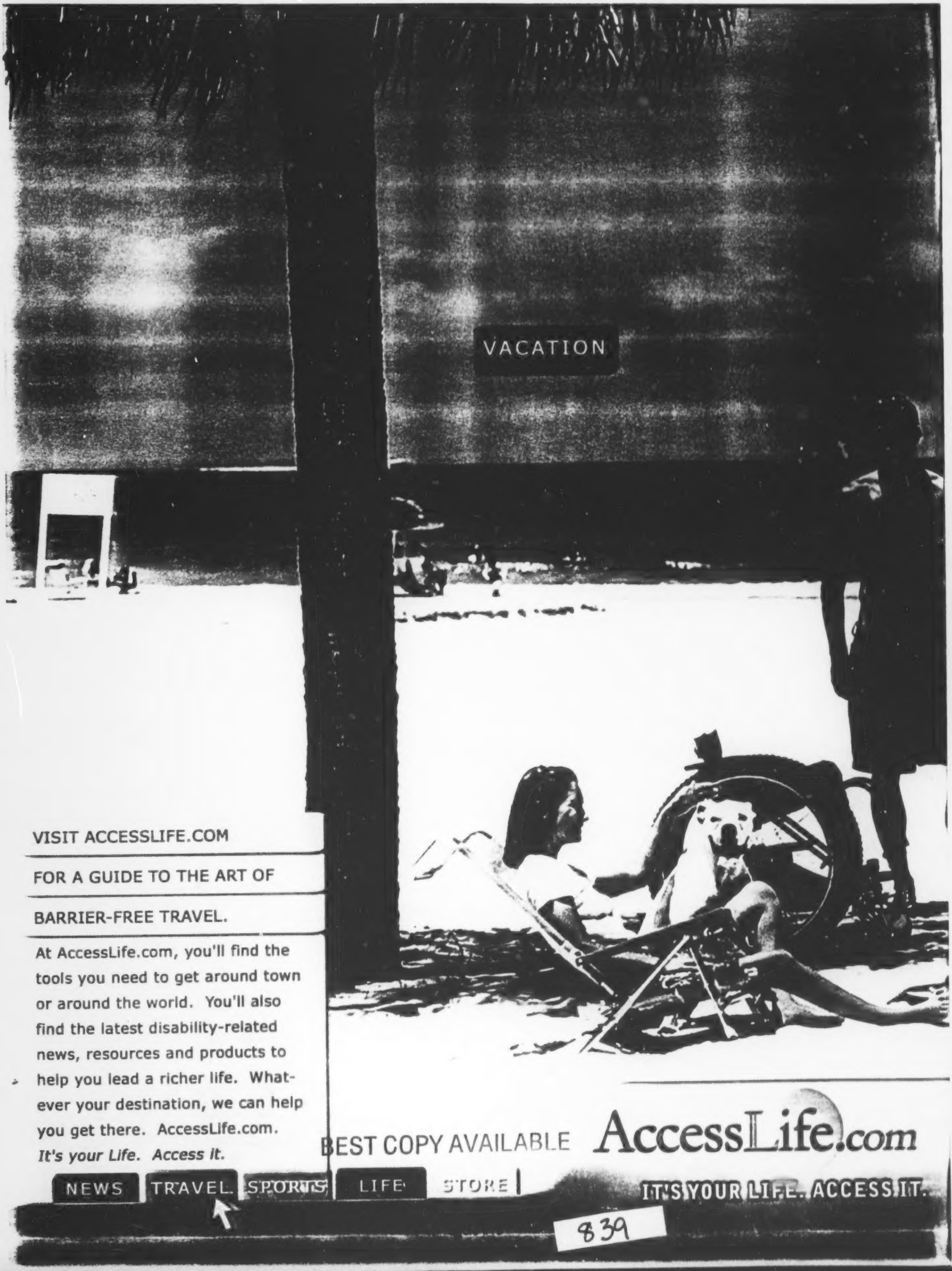

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COVER: Naryan Hernandez, 3, (center) gets the best treatment from members of his healthcare team—his mother Dr. Purnima Hernandez, and neonatalogist Dr. Frank Manginello of Valley Hospital, Ridgewood, NJ. Naryan was born premature, had an intracranial hemorrhage (IVH3), and has stabilized chronic lung disease. He has visual impairment as well as learning, developmental, and speech delays, and was recently diagnosed with multisystem developmental delay. Special thanks to Naryan and Dr. Hernandez, Dr. Manginello, and Maura Gallagher for this photo.

PHOTO BY MICHAEL LONGOBARDI. ART DIRECTION BY ANN WEBER

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- *To reach out to mothers and fathers of children and young adults who have disabilities and special healthcare needs.*
- *To empower parents and professionals by providing practical information and emotional support.*
- *To appreciate that parents are the most important experts in the lives of their children.*
- *To energize parents and professionals.*
- *To share ideas and experiences so parents, professionals, people who have disabilities, and other advocates can learn from one another and better collaborate to serve all children and families.*

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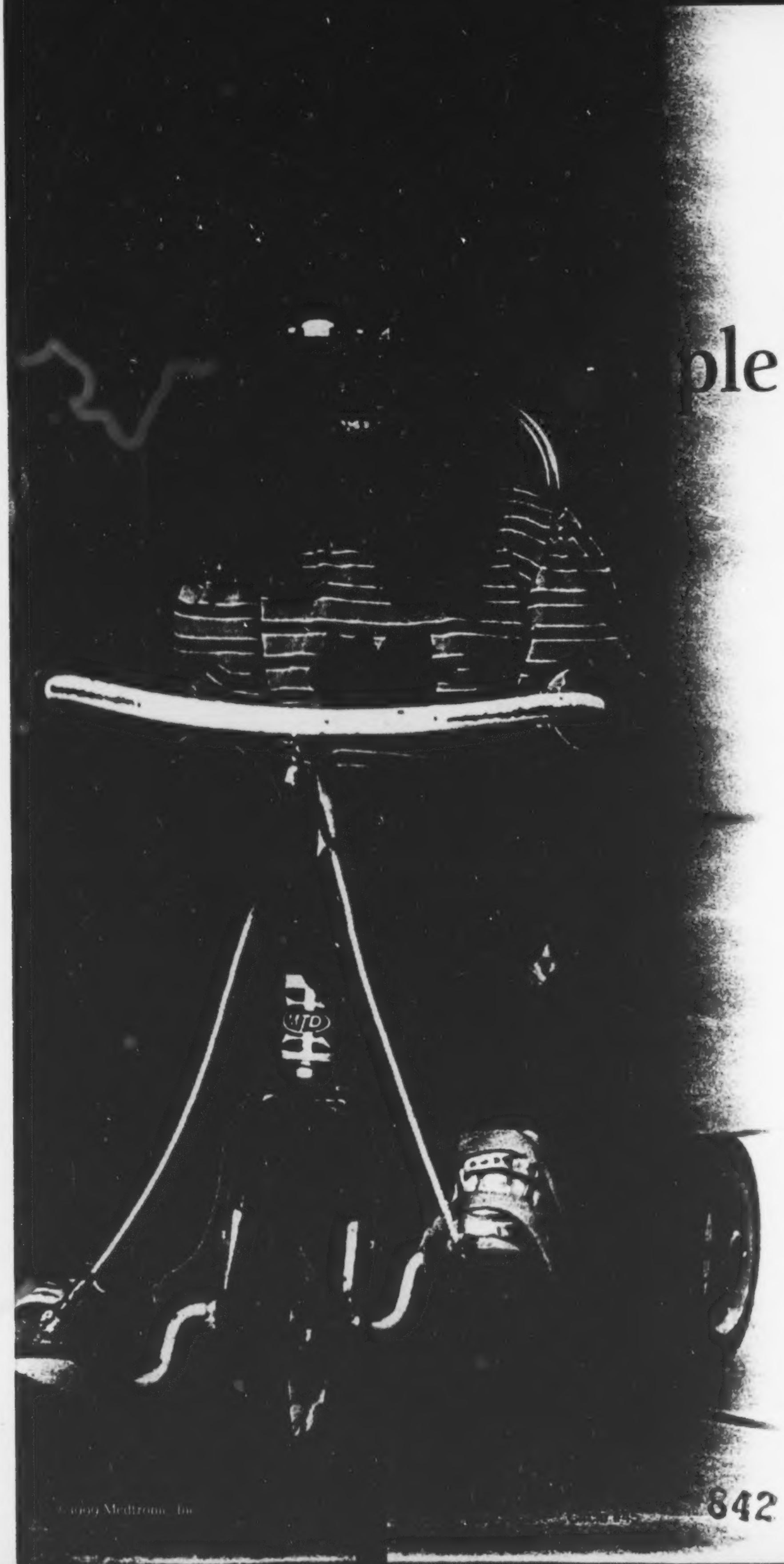

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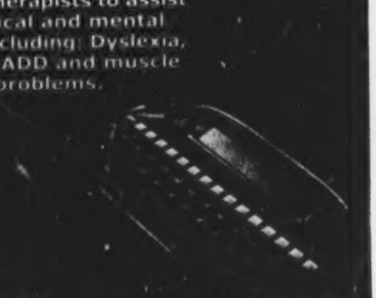

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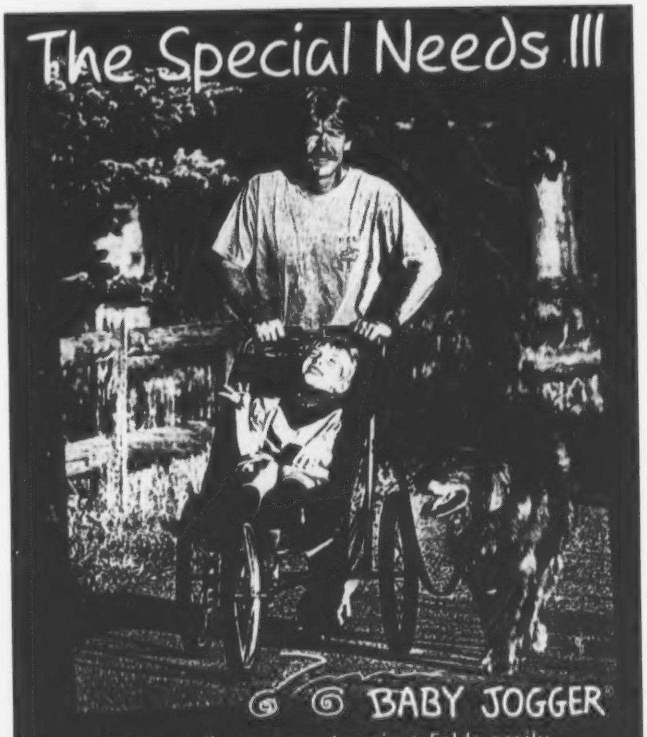

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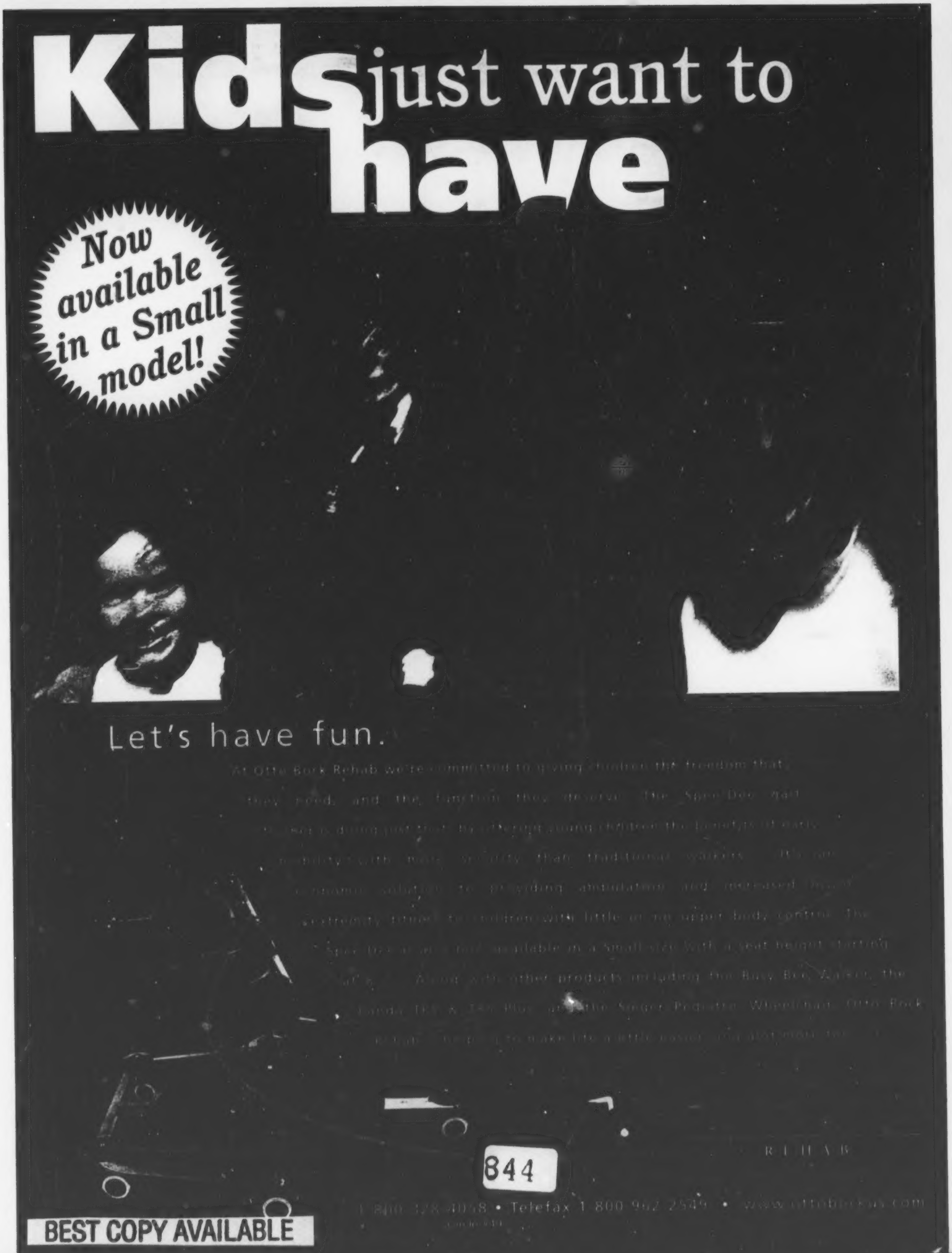

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editor's desk

New Hope Toward Improving Healthcare

In this issue we are introducing three special reports that promise to have a great impact on the dialogue about healthcare practices for children with disabilities.

"Parents as Partners in the Medical Home: Helping children with special healthcare needs," focuses on the Medical Home research project. Finding appropriate healthcare for children with complex special needs is a continuous, ever-growing problem. The American Academy of Pediatrics, with the support of the Maternal Child Heath Bureau, developed the concept of the Medical Home—ideal characteristics that community pediatric practices need in order to meet the special challenges of these children. The Bureau gathered parent perspectives to establish a set of criteria for the Medical Home. The article's authors, Karen Burstein, PhD, and Tanis Bryan, PhD, are the co-principal investigators of the project team that was gathered to analyze the features of the Medical Home concept by examining Phoenix Pediatrics, Ltd., a practice that has adopted the concept. EP has long recognized the commitment and ability of the Phoenix group, headed by Dr. David Hirsch, in serving especially vulnerable children having described how Phoenix Pediatrics functions in detail in a three-part series that appeared from February to April 1998.

Maxwell J. Schleifer, PhD
Editor-in-Chief

Drs. Burstein and Bryan describe what the "Medical Home" entails and the creative research process they used in involving parents in their investigation process. Starting this month and continuing in subsequent issues, they will outline the findings of the Project Team characteristics of the pediatric and community setting which best meet the needs of children and families.

Recent years have seen a rise in attention deficit disorder/attention deficit-hyperactivity disorder (ADD/ADHD) diagnoses. At the same time, treatment methods for the disorder have come under heavy scrutiny. The media have been reporting consistently on the disturbing increase in the number of preschool children with this diagnosis. In "A Closer Look at ADD/ADHD," Vidya B. Gupta, MD, MPH, presents a description of the diagnosis and its attendant problems. In upcoming issues, we will examine the various treatments that exist and the latest research on their efficacy. This fall, EP will publish Dr. Gupta's book on ADD/ADHD, *No Apologies for Ritalin.*

Early medical intervention can be a key to success in the development and promotion of better health in children with special needs. States mandate a number of screening tests for all newborns so that some problems can be minimized or averted. Nevertheless, there is always a time lag between the verification of medical information and its implementation into law. For example, the time lag between knowledge about vaccines and their required use has been heavily reported on. Many children are unnecessarily suffering either because the parents are not aware of the screening procedures or they cannot afford them. It is critical that we highlight this dilemma in order to spur some action. In "Testing for Disorders at Birth," Fern R. Potvin reviews the issues in newborn screening and presents information about the status of different screening tests in every state.

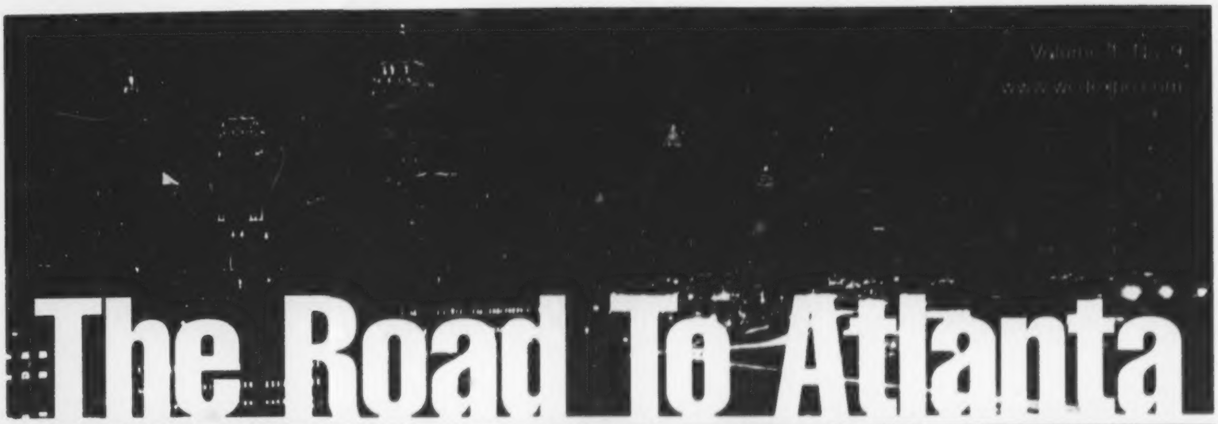
This month also features dealing with some of the mundane problems parents of children with disabilities may face. In "Incontinence: The Medical Story," Michael J. Solomon, MD, a pediatric urologic surgeon, describes the surgical procedures currently used to correct the difficulty. Ronnie Wells, a parent whose son who experienced excessive drooling, describes the heartache this problem caused her son and family as well as the steps they took to find a solution in "Bonfire of Love."

Last month the Americans with Disabilities Act—one of the most important federal laws to protect the rights and further the opportunities of everyone with a disability—passed its tenth anniversary. Dick Thornburgh, former governor of Pennsylvania and father of son who has a disability, was the US Attorney General who was instrumental in the enactment of this landmark legislation. Several months after the law was passed, he wrote an article for EP in which he conveyed his vision and hopes for the ADA. This month we are honored to have Mr. Thornburgh and co-author David R. Fine, also the father of a child with a disability, put some perspective on the legislation and what the future may hold in "Pausing to Reflect on The ADA After 10 Years."

Welcome

EP welcomes Joan Earle Hahn, DNSc, RN, CS, CDDN, to our Editorial Advisory Board. Dr. Hahn is past-president and founding board member of the Developmental Disabilities Nurses Association and an assistant adjunct professor of nursing at the University of California, Los Angeles. Among her projects as a clinician, she is participating in a research project about advanced-practice nursing care and the prevention of hospitalization for individuals with developmental disabilities living in community-care facilities. ■

Maxwell J Schleifer



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Disabilities Experts Will Be Keynoters

Two highly regarded experts on disability issues will be keynote speakers at the World Congress & Exposition on Disabilities in Atlanta, each opening a day's agenda of educational programs aimed at a variety of audiences. John D. Kemp will speak on Friday morning, Nov. 10, and Dr. Julian U. Stein will be the keynoter on Saturday morning, Nov. 11.

Kemp, whose entire career has involved work on behalf of people with disabilities, is vice president of strategic planning at HalfthePlanet.com, a disability community Web portal. Kemp also currently serves a Presidential appointment as a member and chair of the civil rights committee of the National Council on Disability. In addition, he has been president and CEO of the American Association of People with Disabilities (AAPD), which he co-founded. AAPD is a nonprofit membership association organized and operated by people with disabilities. Born with a disability, Kemp uses four prostheses, making him one of only a few executives in his field who has personal experience with a disability.

He is former president and CEO of VSA arts, an international, nonprofit organization dedicated to promoting the creative power in people with disabilities. Founded in 1974 by Ambassador Jean Kennedy Smith as an affiliate of The John F. Kennedy Center for the Performing Arts, VSA arts provides comprehensive programs in the performing, visual and literary arts for children and adults with disabilities. Programs are implemented through a network of affiliates that spans the United States and 83 countries worldwide.

Prior to his VSA assignment, Kemp was executive director of United Cerebral Palsy Associations, Inc., and before that, was general counsel and vice president - development for the National Easter Seal Society. A graduate of Georgetown University in Washington, D.C. and Washburn University School of Law in Topeka, Kansas, Kemp also managed a law firm that advised companies on state and federal civil rights, employment and education laws and policies regarding persons with disabilities. He also has testified before both houses of Congress, the U. S. Department of Justice, the National Institute on Disability and Rehabilitation Research and the U.S. Commission on Civil Rights.

Dr. Stein is a prolific writer and consultant throughout the world in many areas of physical education, recreation and sport, particularly as related to participants with disabilities. With almost 41 years of teaching, coaching and administration experience, he retired in 1990 as a professor in physical education from George Mason University in Fairfax, Virginia. He holds a doctorate in physical education from George Peabody College, now part of Vanderbilt University in Nashville.

He is associate editor of *Palaestra: Forum of Sport, Physical Education and Recreation for the Disabled*; editor of the *Journal of the International Council for Health, Physical Education and Recreation*; and contributing editor of *From the Gym to the Jury*. He has written or edited some 115 books and monographs, published over 400 periodical articles and contributed chapters to numerous professional publications, as well as served as primary consultant for several films and videotapes and on editorial boards, review panels and advisory committees. He also serves as an adjunct professor of physical education at the University of Tennessee in Knoxville.

During his academic career, he assisted teams and individuals competing in wheelchair track and field, and served as executive director and consultant of the Unit on Programs for the Handicapped of the American Alliance for Health, Physical Education, Recreation and Dance (AAHPERD). He developed and administered for 15 years Physical Education and Recreation for the Handicapped: Information and Research Utilization Center at AAHPERD, one of the first information and retrieval centers worldwide dealing with physical education, recreation and sport and the first to deal with those with disabilities.

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Search & Respond

About Search & Respond

Search and Respond is an opportunity for our readers to exchange information about their practical experiences in meeting the everyday challenges of life with a child or adolescent who has a disability. In this column, "S" represents Search letters and "R" represents Respond letters received to a previously printed Search. "Instant S&R" is a new feature which represents e-correspondence we have downloaded from our Web site. All Responds are forwarded to the writers of the original Searches; some are published. Published letters may be edited for purposes of space and clarity. We also expect parents to consult appropriate professionals.

When sending correspondence, please indicate whether it is a Search or a Respond. For Responds, be sure to note in which issue the original Search letter appeared. Please remember to include a phone number on all correspondence, in the event that more information is required. Write to: Exceptional Parent, Attn: Search/Respond, 555 Kinderkamack Rd., Oradell, NJ 07649-1517; Fax to: (201) 634-6570; E-mail to epedit@aol.com; or visit Search and Respond on our Web Site: http://www.eparent.com.

For information about specific disabilities, contact: the National Organization for Rare Disorders (NORD), 100 Rt. 37, PO Box 8923, New Fairfield, CT 06812; (800) 999-6673; (203) 746-6518; Web site: http://www.rarediseases.org. Also, see the "National Resources for Specific Disabilities" directory in Exceptional Parent's 2000 Resource Guide (January 2000, starting on page 30).

Each month, Chris Feudtner, MD, PhD, reviews Search & Respond for accuracy and completeness. Dr. Feudtner is a pediatrician at the Pediatric Care Center of the University of Washington in Seattle, and is currently a Robert Wood Johnson Clinical Scholar. Look for Dr. Feudtner's comments on certain Search & Respond letters.

S Dependent son with high IQ

Our son is 15 and has spastic cerebral palsy. He is completely dependent on others for all of his needs. However, he has a normal IQ and is mainstreamed into regular classes with a full-time aide. He eats a regular diet, but needs someone to feed him and take him to the bathroom. Our son speaks, but it is difficult to understand him because of his limited oral abilities. We are looking for a computer system that would allow him to work on his own. We are also looking for other parents whose children are "high-functioning" but have severe limitations. Our son wants to have a job and be on his own some day.

LN, via the EP Web site

EDITOR'S NOTE:
You may want to contact the National Office of the Alliance for Technology Access (ATA) to find the ATA center in your state. Their phone number is (415) 455-4575; Web site: http://www.ATAccess.org; and E-mail: ATAinfo@ATAccess.org.

S Sensory room

I am looking for information about the benefits of sensory rooms for children with disabilities. I know they have been used with children who have autism and have worked well, but I would like some more information. Where can items be purchased if one wished/planned to start a sensory room?

CD, via the EP Web site

EDITOR'S NOTE:
Ingrid Provident is an occupational therapy instructor at Duquesne University, Pittsburgh, PA. She wrote an article entitled "Adventures for the Senses: Fun is all around at Sensory Adventure Camp" (EP, June 2000). She can be reached at :
Duquesne University, 227 Health Science Bldg.
Pittsburgh, PA 15282
Telephone: (412) 396-5411
E-mail: provident@duq.edu

S Choreoathetoid cerebral palsy

My son was born prematurely (he is a surviving triplet). He is now 21-months old and was recently diagnosed with choreoathetoid cerebral palsy (a form of cerebral palsy characterized by abnormal involuntary body movements). This is a rare diagnosis for an infant, and we are eager to locate other parents who have an infant with this diagnosis. We are also looking for input on types and amounts of physical/occupational therapies to allow him to be self-ambulatory and improve his motor skills.

LM, Massachusetts

R Behavior modification

SB (May 2000) has an 18-year-old son with cerebral palsy, epilepsy, and mental retardation. His son hits and swats at people, and because of his size, may seriously hurt someone unintentionally. It was suggested to SB that electric stimulation therapy be used to help his son control these behaviors. SB thought this sounded potentially cruel, especially because his son would have to be temporarily institutionalized while his caregivers learned to use the device.

I suggest that you find a behavior analyst with experience in Positive Behavior Support to work with your son. I have 20 years teaching experience with children with special needs. My guess is that your son is using his swatting as a means of communication. Medication may not help, so he probably needs to be taught other ways to communicate boredom, frustration, etc., and also to ask for breaks, changes in activities, etc. I am not totally opposed to aversive treatments, but I believe that they should only be used as an absolute last resort. They should be used only under carefully controlled conditions, and only for behavior that endangers the life of the individual and/or other people. I would suggest that you try your state's University Affiliated Program.

CH, Florida

EDITOR'S NOTE:
To find the University Affiliated Program in your state, contact the American Association of University Affiliated Programs at 301-588-8252. Their Web site is http://www.aauap.org.

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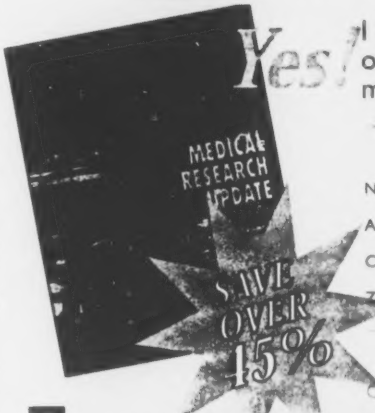

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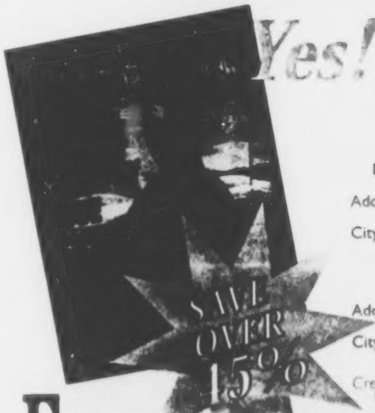

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Search & Respond

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R I worked for four years at a behavioral school specializing in this type of treatment. My suggestions are: Know that skin shock therapy is a last-resort option. Many clients improve using a therapy with some other less drastic consequences. For instance, one client improved dramatically when mitts and a helmet were put on her for one minute every time she swatted at someone. If you are uncomfortable with skin shock being used on your son, a different adverse-response technique could be used. The idea is that some response your son does not like is applied, consistently and immediately, following the behavior (swatting).

Learn to use the technique yourself. Many parents use the SIBIS (Self-Injurious Behavior Inhibiting System) to help their self-abusive or aggressive children get control of their behavior at home. This is a skin shock device that can be prescribed by a psychologist for use in the home or at school. The treatment program is much more effective when parents understand it and follow it. Skin shock therapy has improved the quality of life for many individuals who would otherwise be in strait jackets or drugged. It is a tool of last resort that should be used only as part of a regimented program of behavior modification.

SO, Rhode Island

R Please carefully consider the use of any type of aversive therapy to manage behavior. There are many other options that can be as effective or more effective without using painful experiences. Behavior is often a form of communication. You mentioned that your son is nonverbal. His swatting may be communication, whether he is bored, hungry, or simply wants attention.

I often look at what is happening just before the behavior occurs, then examine what happens just after the behavior. Often, there are many clues to the cause of the behaviors when observed carefully.

My son is now 22-years old and is nonverbal, has autism, cerebral palsy, mental delay, and seizures that do not respond to treatment. When he was younger, he would become frustrated or angry and drop to the floor and bang his head.

There were times he would really hurt himself. We recognized that his behavior was communication, and began to analyze events before and after the behavior. We did not use anything that would hurt him, but when he dropped to the floor, we would hold him so he was unable to bang his head. Then we looked at the situation. Was he trying to avoid something? Was he frustrated? Bored? Tired? This helped us understand things that are important to him while letting him understand that it was unacceptable to hurt himself. It took a long time, but the behavior changed.

I have several suggestions:

1. Take him to his doctor and make sure he is healthy and not in any pain.
2. Find a behavioral psychologist who is willing to help you analyze his behavior and develop a plan to change his behavior in a loving way.
3. It is important that you are comfortable with the professionals who help you care for your child. If you have someone who is advocating therapies you do not agree with, discuss your concerns.
4. Medications can help.

I am passionate that we care for all people, especially those with disabilities, in a loving way.

KC, Georgia

Instant S&R

S **Need a beach chair**

My daughter is 5, and has spastic diplegic cerebral palsy. She walks with a walker or uses a wheelchair for long distances. My family spends a week at the beach each summer, and my daughter's walker will not work on the sand. Up until now, I have been carrying her from the street onto the sand where she can crawl. But she cannot crawl on the hot part of the sand, or on the pathway through the vegetation to get to the beach. Has anyone ever used a "beach wheelchair"? I have seen them advertised for rent, but they are pretty expensive and I do not want to rent one if it does not work well. Has anyone had any experience with these?

JB, via the EP Web site

R Try contacting a company in Norfolk, VA, called Rolleze. They make beach chairs with large wheels and offer several other options that might help you.

SK, via the EP Web site

EDITOR'S NOTE:
Natural Access also makes a chair, called Landeez that is made for rolling on sand. Their phone number is (800) 411-7789. Another company is Deming Design, Inc. Their phone number is (850) 478-5765; Web site: http://www.beachwheelchair.com; and E-mail: kmdeming@aol.com.

S **Hip surgery**

My youngest daughter has cerebral palsy. She is 19-months old, and we just found out that she has a dislocated hip. Our orthopedic surgeon told me that our only option is surgery. I would like to hear from other parents who have dealt with a child who needed hip surgery.

Diane, via the EP Web site

R My 8-year-old daughter has undergone hip surgery three times. These kids are resilient. She had less trouble recovering from the first surgery than the last, and enjoyed all the extra attention she got from everyone at the hospital and at home. Children are less likely to remember the pain and the discomfort when they are younger than when they get a little bit older.

CC, via the EP Web site

R Our daughter had hip surgery last year, and it was very painful for her. She was 2-years-old at the time, but we felt it was best to go ahead and address the issue. They cut the bone, reposi-

continued on page 20

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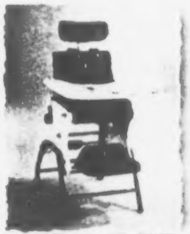

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Circle #65

continued from page 19

tioned it at a better angle, and then used metal plates and screws to hold the bone while it healed. Although the surgery itself was traumatic (for everyone!), she now has good alignment and we have the comfort of knowing that she probably will not remember it. If you hope for your child to have any sort of independent mobility, I think it is a good idea. Just be prepared for a rough first 24 hours.

SM, via the EP Web site

Sleep problems

My 13-year-old daughter has hemimegalencephaly (one side of the brain is enlarged), hydrocephalus, and an intractable seizure disorder. Her seizures are under control with a combination of drugs, but a 24-hour EEG showed that she experiences constant underlying abnormal electric activity in her brain. Our biggest problem, however, is dealing with her sleep patterns. Since reaching puberty, she stays awake (and is very demanding) almost all night every night, and sleeps all day. Not only is it impairing our ability to function, it is robbing our daughter of school-provided homebound therapies and special education services to which she is entitled. We have consulted her neurologist, her pediatrician, and even an endocrinologist, but none of them can offer a solution.

Ginny, via the EP Web site

When my daughter was at Kennedy Krieger Neurobehavioral Unit, I saw that some of the patients on the ward were having sleep problems like the one you described. They would keep the children awake all night at first, allowing them to go to sleep at 5:30 am and gradually move the sleeping time back earlier and earlier.

Sheree, via the EP Web site

EDITOR'S NOTE:
You might consider asking your child's physician for a referral to a pediatric sleep clinic.

Special thanks to this month's guest reviewer, Frank P. Manginello, MD, FAAP. Dr. Manginello is a clinician at Valley Hospital, Ridgewood, NJ, and is the Director of Neonatology and the Medical Director of Child Development.

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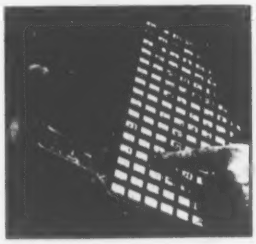

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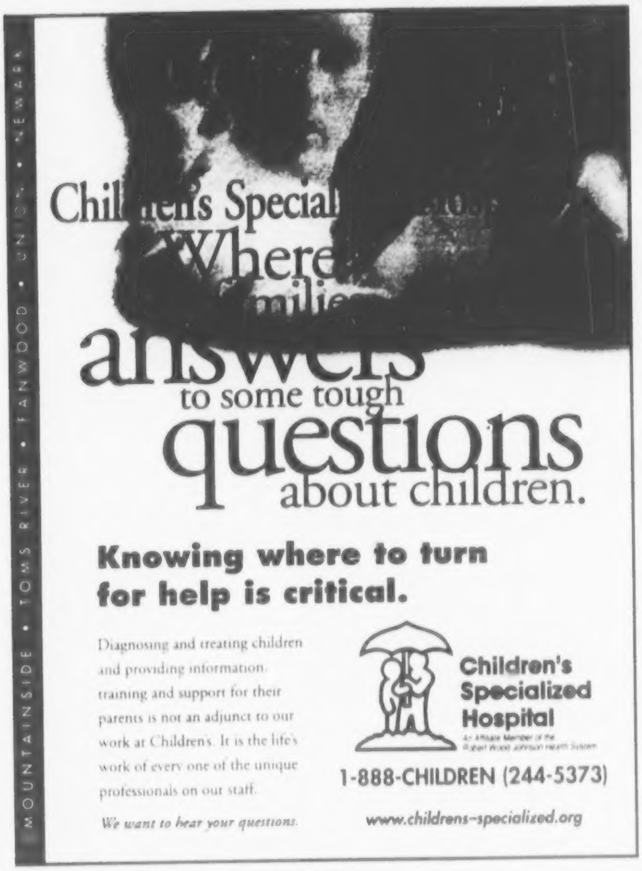
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Healthcare

Incontinence

THE MEDICAL STORY

by Michael J. Solomon, MD

Among the many challenges faced by people with disabilties, their parents, and families, the problem of urinary incontinence remains a high priority. This is because control of bodily functions is a personal and private concern involving the genitals and "private parts," and it affects feelings of self-confidence and self-worth.

Perspectives in incontinence

People with disabilties such as spina bifida, those with cerebral palsy, and some muscular dystrophies experience incontinence involving nerve and muscle control of the bladder and urinary channel. Disabilities also include those with abnormal formation of the bladder, such as bladder extrophy, where the abdominal wall fails to close, leaving the inside of the bladder exposed; or epispadias, where the urinary opening is on the top of the penis.

Treatment considerations for these individuals must be placed in perspective in terms of priorities. These priorities are:

1. Preserving kidney function
2. Avoiding urosepsis (life-threatening spread of urine infection to the bloodstream)
3. Achieving urinary continence
4. Maximizing independence

People with abnormal bladder function are at risk for problems that may shorten life due to infections, kidney failure, pressure sores from wetness, or high blood pressure from kidney damage. Most of these problems can be avoided. Children born with these problems now can benefit from lessons learned in the past.

Looking back

Prior to the 1950s, many people with incontinence were treated by leaving an indwelling catheter to drain the bladder into a bag. The constant contact of the catheter with the urine made infection, stones, and eventual erosion of the urine channel almost unavoidable.

In the 1950s, Dr. Bricker developed the ileal conduit, and through the 1960s and early 1970s this was thought to be the solution to the problem. The ileal conduit worked by bypassing the bladder and substituting an isolated segment of intestine to carry urine from the tubes draining each kidney to a stoma (an opening on the abdomen) and wearing a stoma appliance (an external bag to collect urine). This procedure avoided the need for an indwelling catheter.

Long-term complications, however, from the loss of kidney function to the undesirable aspects of having a stoma and a bag led to abandonment of this procedure.

The next procedure to be developed was urinary undiversion. This was accomplished by the means of a surgical procedure in which a segment of intestine could be added to the bladder to increase bladder capacity. A variety of techniques were developed to improve bladder control. The most significant of these was intermittent catheterization.

Intermittent catheterization—a safer way

Intermittent catheterization involves emptying the bladder periodically by using a clean, non-sterile technique that preserves both kidney and bladder function. Intermittent catheterization, performed whenever possible by the individual, and if not possible, by a caregiver, has achieved the goal of protecting kidneys, preventing infections, and allowing increased independence.

There is often significant resistance to the use of intermittent catheterization on the part of individuals and families. This is partly because it is not obvious that intermittent catheterization is safer than an indwelling catheter. It seems as if there would be an increased risk of injury and introduction of infection by the repeated passage of a catheter. There may also be significant psychological resistance, since most people grow up being told they should not think about their genitals, and by no means should they put anything in them. This resistance is usually overcome if the individuals give the technique a chance and recognize that it does, indeed, allow them to function and that it protects them.

The teaching of intermittent catheterization depends on patient, knowledgeable nursing personnel, and scheduling sufficient private time, free of interruptions or distractions. The only factor that convinces people to use intermittent catheterization is the fact that it works better than any alternative. Initial fears are overcome when they see that it is not painful or difficult (i.e., if you go into a tunnel at one end, you can only come out at the other. There is no chance of coming out in the wrong place or causing damage to another organ.).

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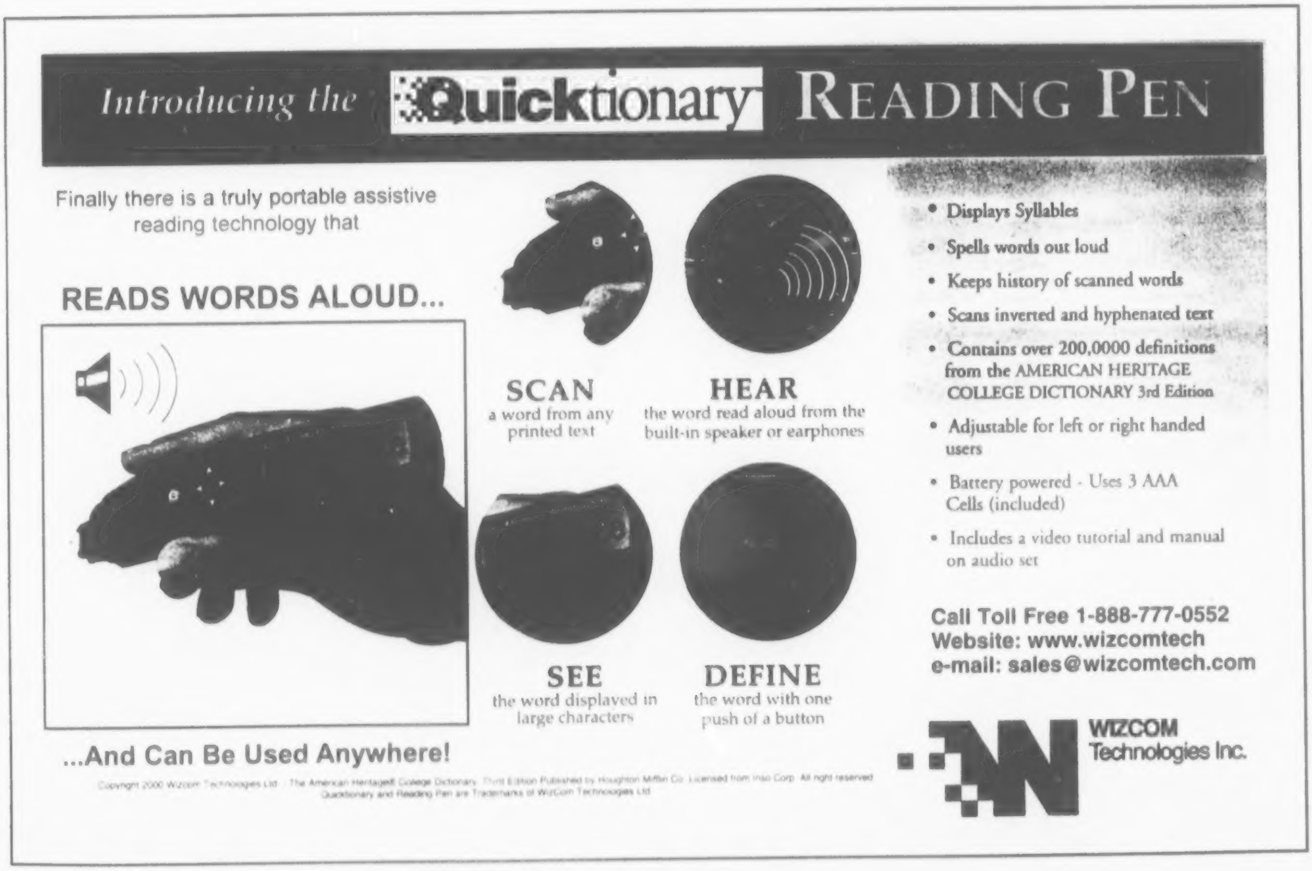
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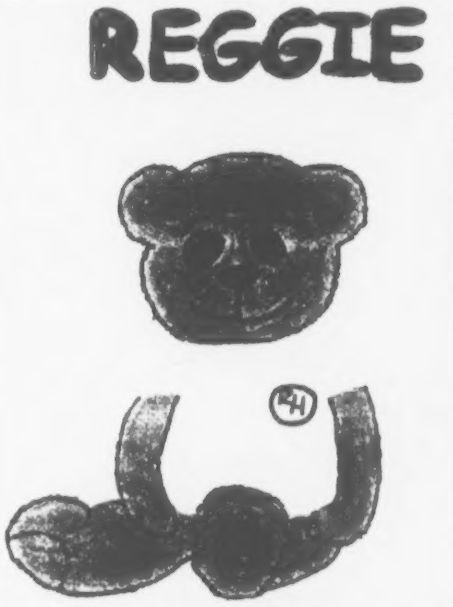
continued from page 23

In males, flexible catheters can be used. These catheters are kept in a plastic baggie between uses. The patient washes his hands with soap and tap water before and after passing the catheter each time. A single catheter can be used for an arbitrary period of two to four weeks, after which it is discarded and a new catheter is used. In females, because of the physical difference in the urethra, hollow metal catheters can be used. The metal catheters are kept in a container with alcohol between uses and are again washed with soap and tap water before each use and returned to the

Just Like You

A mother and son offer support

by Brenda Fregger



Reggie the bear is the main character in "Just Like You!" which is based on Ryan Fregger's experiences with incontinence, both physical and emotional.

My son Ryan has incontinence caused by a neurogenic bladder, a rare type of nerve damage of the bladder and bowel from spina bifida occulta. He also had an obstructed urinary sphincter muscle, along with kidney damage caused by a congenital obstruction of the left kidney. My son has been through two major kidney surgeries and countless minor surgeries and procedures of both the bladder and kidney, and he must endure constant invasive medical care.

You see, my son's medical problems are rare and there are no support groups of any type. We have struggled in complete isolation, trying our best to cope with the devastation of his medical problems. The emotional and social impact of my son's medical problems are so very difficult and painful, and it is heart-breaking to see him struggle every day with this! I could not just sit back and watch him suffer and do nothing, but we had very limited resources and no support. I watched in horror as my happy, funny, and full-of-life little boy became quiet, sad, and withdrawn. Ryan came home from school every day in tears because he was teased for wearing diapers or having wet pants, and it was tearing both of us apart!

I started to do research to find support groups, protection products, even another person with similar problems. I found nothing! I knew that I was on my own in dealing with this and helping my son deal with it. It was the most difficult and painful thing I have ever faced.

Brenda Fregger and her son Ryan, 12. Ryan was the inspiration for and co-author of the book "Just Like You!" which Brenda published.

Putting it down on paper

I kept a journal from the beginning of my son's medical problems. Writing was my only outlet, and it helped me immensely. I thought that it could be a good way for Ryan to get his feelings out, too. It took two years, but we turned my journal and Ryan's own account of what he has been through and how he feels about it all into a children's book. After some pressure from friends and family to do "something" with it, we donated the first and, at the time, only copy of our book entitled "Just Like You!" to Sacred Heart Children's Hospital in Pensacola, Florida, where Ryan had his kidney surgeries. It was the best thing we could have ever done! We left the hospital that day changed, like a weight had been lifted from us. No longer did we feel like such victims of his medical problems, and the feeling of our story being able to help another child made us both feel that all our pain and suffering was not in vain. It was our first real step toward healing.

Our local media picked up on what we had done and we made the local news. My son was "famous" at school for a few days, but more than that, he was no longer teased. The other kids thought that what he had done was very brave and special! I saw him change—he was back to his old self: happy, funny, and enjoying life again. He had found the strength and courage to stand up and fight to be treated like every other kid! This has helped him more than I had ever hoped or dreamed. Because of our local media attention, over 50 copies of our self-published book are now in children's hospitals container.

[We have found that 2-liter soda bottles, before they are expanded in the factory to contain soda, are just the right size to contain metal catheters, and we have been able to obtain these from the manufacturers for use.]

While many individuals prefer to have more than one catheter, a single metal catheter can last for years. About one half of individuals using intermittent catheterization will have bacteria in the urine. When

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Helping Other Children

The Simon Foundation is the first and only organization that has taken steps to offer support solely for pediatric urology issues. I am helping the Foundation develop a program that will include an interactive Web site offering help and emotional support for children with incontinence/urology issues and their families. In a cartoon-style format, using kid-friendly language and from a kid's point of view, Simon, a cartoon child and "spokeskid" for the program, will talk to kids, listen to them, and understand everything they are going through.

Although Simon is a friendly character, he is armed with knowledge, wisdom, information, and resources from pediatric urologists, nephrologists, neurologists, nurses, and psychiatrists to give children and their families useful and helpful information, tips, suggestions, and strategies for coping with the effects of living with incontinence/urology issues.

There are two Internet E-mail support lists that deal with urology issues. They are: LFSN Support List (Lipomyelomeningocele Family Support Network), which can be contacted via E-mail at lmc-tcs@Avenza.com; and the Neuro-Incontincence Support List, which deals with damage to the bladder, neurogenic bladder, urinary sphincter problems, etc., and they can be contacted at the following E-mail address: neuro-incontinence@egroups.com. Both support lists are free of charge. These lists are dedicated to providing moral and emotional support (via E-mail) for parents and caregivers.

As important as it is for parents to seek out help and support, it is even more important for children to have support.

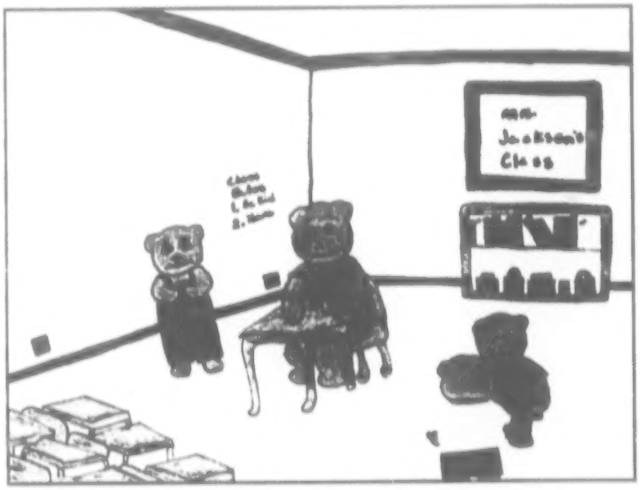
—Brenda Fregger

across the US. Though writing our story helped my son, we also found that the best thing in life that you can ever do is reach out to others and offer help, support, and compassion.

The strength and courage that I have learned from my son, has enabled me to become very involved in creating emotional support systems for families that have children who deal with the emotional effects of any medical problem, and I have started a local support group. I have also convinced a large organization, The Simon Foundation, dedicated to urology issues, to include an emotional support program for children who experience urology and incontinence issues (see Helping Other Children, above).

The rewards from all this are truly immeasurable, and to see my son coping so well with the struggles of his medical problems and to know that he really feels very good about all that he is, is the most wonderful thing in the world for me. Although Ryan continues to face medical problems, with upcoming bladder surgery, he is a happy, active kid. Through his own pain and suffering, he is reaching out to other kids to offer support and understanding. In my eyes, he is a very special and brave little guy! Ryan said to me, "Mom, is it okay if I'm kind of glad that I have a kidney problem? I mean...'cause if I was 'normal' then we wouldn't have written our book and we wouldn't be able to help kids like me!" It was at that moment that I realized just how much doing all of this had helped my son face his problem. We hope that our story can be an inspiration to others, to show them that there are silver linings in dark clouds. Because if I could find my silver lining, then it is possible for anyone!

Brenda Fregger, her husband Michael, and Ryan live in Mary Esther, FL. Brenda can be contacted via E-mail at mafregger@sprintmail.com.



Illustrations like these, along with text, portray what incontinence is all about.

"Life is so much easier"

A family's experience with bladder augmentation

Lisa Brandenburg, 9, from Frederick, Maryland, underwent bladder augmentation surgery last year. Born with spina bifida, Lisa had a vesicostomy when she was an infant because her bladder was not big enough, and a problem with the bladder neck allowed urine to reflux back into her kidneys.

Due to the vesicostomy (a surgically created opening below the navel through which urine drains continually) she had to be kept in diapers, and there was a constant losing battle to keep her and her clothes dry. Not only that, as Lisa got older, it became very difficult to find places where her diaper could be changed away from home. Lisa uses a wheelchair and must be transferred to a changing table to have her diaper changed. Changing tables in public restrooms are not made to accommodate larger children. According to Lisa's mom, Ruthie, however, most important was that Lisa did not want to be in a diaper. Ruthie remarks that Lisa wanted to be independent and have control and privacy in the bathroom.

Lisa's doctors decided that a bladder augmentation might be a solution. Lisa had to undergo numerous tests of her bladder and kidneys to determine if she was even a candidate for bladder augmentation. Ruthie remembers that Lisa was extremely eager to have the operation.

The operation uses body tissues to make a "patch" to enlarge the bladder, and then a new passage is made for the urine to leave the body through an opening called a stoma. The stoma is usually placed though the navel, but it can be placed in other locations, depending on individual preference and convenience.

Ruthie felt that before the bladder augmentation was performed, Lisa should be in good health, strong, and have an adequate body weight. Ruthie remembers that her family started preparing for Lisa's surgery about one year before it took place.

The surgical procedure, which normally takes about 6 to 8 hours, ended up taking 18 hours for Lisa.The problem was that Lisa's appendix, with which the surgeons had planned to construct a new bladder, was too small. They then had to use a piece of her lower (bowel) intestine for the bladder augmentation, and created the stoma using her appendix.

After her surgery, Lisa was in the hospital for about 10 days. She had a foley catheter (a soft, thin, rubber tube with a balloon on the end that is inserted into the bladder and used to drain urine) and an emergency catheter. Her mother remembers, "She was full of tubes!" These had to remain in place, even at home, until the stoma healed and could be accessed with an intermittent catheter. There were many problems with infection, and Lisa was back in the hospital one week after she came home. "Every child is different, and every child will react differently to this procedure. Lisa's problems were unique to Lisa," Ruthie says.

Lisa Brandenburg, 9, (left) and her sister Rachel, 11. Lisa underwent bladder augmentation surgery last year.

Three months after the bladder augmentation, Lisa was catheterized though her stoma for the first time. Ruthie spoke openly about catheterizing her daughter. "Many parents are afraid to do it; they think it will hurt. But you have to realize that NOT catheterizing your child is what will hurt them." When Lisa was able to be catheterized, Ruthie made sure that all of the family members, including grandparents and caregivers, could handle the procedure. Ruthie says, "When you put the catheter in the stoma, you can actually feel the flap of skin opening, like a door. It's really very easy."

Lisa needs to be catheterized every four hours. "A lot of parents whose children have this procedure ask, 'Am I going to be up in the middle of the night all the time, catheterizing?' They have to realize that every child is different. I know a family whose son needs to be catheterized every six hours, and some go longer than that."

The most noticeable outcome of the bladder augmentation was the change in Lisa. "Life is so much easier," says Ruthie. "Lisa is totally accepted at school. She can go into a bathroom, use the catheter, and it's done! It is really the change in her self-esteem that has amazed us. She has grown so much as a person."

As for the difficulty in teaching Lisa how to catheterize herself, Ruthie said, "She was able to do it the same day I taught her. It took 15 minutes to explain it to her. After all, there's only one way to do it."

Ruthie remembers how it would have been easier for her and her family had they known other families to talk to who were in the same situation. She has graciously offered to speak to any families about bladder augmentation. We thank Ruthie and her family for sharing their story with EP.

Ruthie Brandenburg and her husband, David, live in Frederick, MD with their daughters, Lisa and Rachel, 11. Parents can reach the Brandenburgs by telephone at (301) 898-3356, or by E-mail at rufus318@email.com or rlb@netcrafters.net.

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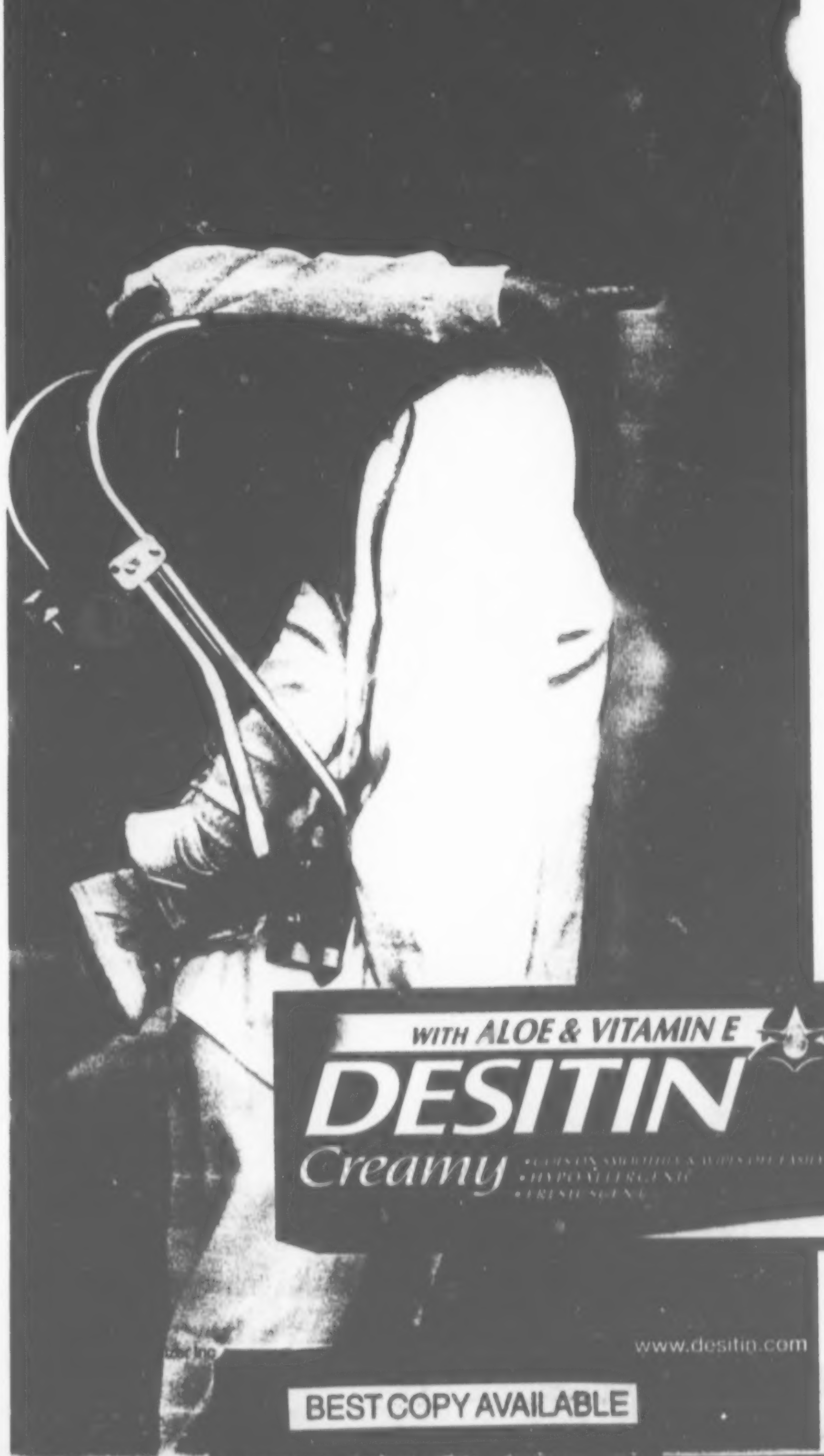
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continued from page 25

the bacteria remain in the urine and do not affect the bladder wall, positive urine cultures do not require treatment. The significant factors that protect the bladder with intermittent catheterization are catheterizing regularly (usually about every four hours during the day), and most important, emptying the bladder completely. Maintaining a high state of hydration by drinking water is also helpful since this improves the "washout" mechanism by which the bladder is cleansed of bacteria.

Bladder augmentation

For those patients who cannot store urine because of reduced bladder capacity, bladder augmentation with intermittent catheterization can be used. About 20 to 30 percent of children with spina bifida have "failure to store" bladders because the outlet is open and the bladder will leak. These individuals present an ongoing challenge for the urologist. A variety of surgical techniques have been used to try to increase bladder control. The prosthetic urethral sphincter is a device, similar to a blood pressure cuff, that is placed around the bladder neck or "urethra" and fills with fluid from a reservoir adjacent to the bladder within the body. Flexible plastic tubing attached to a pump device placed in the scrotum or labia connects both of these segments. By pushing on the pump, the fluid from the cuff moves to the reservoir, allowing the bladder to empty. After a few minutes, the fluid returns to the cuff and provides continence.

This is a prosthetic device, however, and is subject to mechanical failures such as leakage of the fluid, malfunction, and the cuff being too loose or too tight. Alternative techniques for increasing outlet resistance include a variety of procedures that lengthen and narrow the bladder. These techniques can be done in association with bladder augmentation procedures and with intermittent catheterization.

For individuals with insufficient bladder-outlet resistance (the failure of the bladder to store urine), creating a urinary diversion represents a safe and effective alternative to the prosthetic sphincter or bladder neck procedures. The procedure to create the urinary diversion involves isolating a segment of bowel from the remainder of the bowel, with its blood supply intact. The segment is fashioned into a spherical reservoir and the ureters are attached to the reservoir to allow urine to drain from the kidneys into the reservoir. The opening from the reservoir is usually through a passageway, called a "stoma" in the belly button or the abdominal wall, and the reservoir is emptied every four hours during the day by passage of a catheter through the stoma.

Drugs that may help incontinence

In addition to the surgical techniques outlined above, a number of pharmacological agents can be used to affect bladder control. These include so-called "anticholinergic" agents, such as Ditropan®, Detrol®, or probanthine. These medications reduce the pressure in the bladder by relaxing the muscle in the bladder wall, allowing increased bladder capacity at low pressure. There are medications called "alpha stimulating agents" that help to increase muscle tone in the bladder neck and urethra and increase outlet resistance. Sudafed®, a commonly used decongestant, is the most frequently used of these medications. While these medications are often used as adjuncts, and may be very helpful for individuals with borderline function, they are often not a sufficient alternative to surgical management.

Using timed voiding

For people with cerebral palsy and spastic quadriplegia, difficulty with mobility and ambulation leads to episodes of incontinence when they are not able to access the toilet in time. The most useful regimen for these people is the use of timed voiding. This allows them to attempt to urinate every three to four hours, before the bladder reaches capacity and empties itself. While the bladder muscle is mostly an involuntary muscle, the sphincter muscle is a voluntary muscle and, therefore, fatigues before the bladder muscle. While it may be difficult to initiate voiding voluntarily because the sphincter is in spasm, it will usually relax enough to allow the bladder to empty. The technique of supra-pubic tapping, by which the bladder is stimulated by tapping with the fingers on the belly just above the pubic bone 10 or 15 times prior to trying to void, will often be sufficient to fatigue the sphincter and allow urination to start. Bladder augmentation, intermittent catheterization, and urinary undiversion are often unnecessary for people with cerebral palsy.

The bladder extrophy and epispadias complex represents an additional challenge. In this situation, in which the bladder is open to the abdominal wall at birth and the genitals and urethra do not form normally, multiple surgical techniques are often necessary to reconstruct the bladder and outlet resistance. Often, continent urinary diversion represents a preferable alternative.

Keeping an eye toward the future

While we can take significant pride in the progress that we have made, it should be apparent that the present state-of-the-art represents a work in progress. Medicine is, however, a constant effort to do the best we can while recognizing that our knowledge and techniques are limited. Additionally, the essential need for support, encouragement, and enthusiasm on the part of personal caregivers and other healthcare professionals remains at the forefront in helping children with incontinence deal with the issues involved.

For the present, we must use the techniques that are available and not delay them while awaiting future breakthroughs. These surgeries are generally applicable at whatever age the person with incontinence becomes capable of participating in his or her own care, often at about age 9 or 10. The tragedy is not that some children may be incontinent, or that they may require invasive surgeries. The tragedy is that some children suffer with limitations of social interaction, ostracism by their peers, or reduced feelings of self-worth because they either do not have access to treatment or treatment options are not considered when their urinary incontinence can be corrected. ■

Michael J. Solomon, MD, is a pediatric urologic surgeon practicing in East Brunswick, NJ.

Parents As Partners In The Medical Home

Helping Children with Special Healthcare Needs

by Karen Burstein, PhD, and Tanis Bryan, PhD

"I enjoy being involved in the Medical Home Project because it gives me a chance to share my experience in a positive way with the hopes of making a difference in someone else's life. For the first time I feel like I have a voice in my child's healthcare. Doctors and nurses actually listen to what I say" Mae Moore, parent participating in Phoenix Pediatrics' Medical Home Project.

For years parents of children with serious, chronic, complex healthcare problems have been struggling with problems that parents of healthy children do not face. Because these children often require multiple services, they spend a lot of time in different offices and clinics coping with multiple sets of paperwork. Because these children are medically complex, they have to seek out physicians who are experienced and willing to work with them. Because these children are not only medically complex, but financially costly, they have to deal with health maintenance organizations too often reluctant to provide them and their physicians with the support needed for adequate care.

Medically complex children

Children with special healthcare needs (CSHCN) have or are at risk for chronic physical, developmental, behavioral, or emotional conditions and who require health and related services of a type and amount beyond that required by children generally (MCHRB, 1997). These conditions may limit their growth, development, or ability to do the usual activities of children their age, and often require special medical and other support services. They are a diverse group, having over 3,700 chronic conditions. The three most common conditions are: respiratory disorders, musculoskeletal disorders, and attention deficit disorders. *Newacheck and Taylor* (1992) estimated that one or more of these conditions affect over 20 million children and youth, or 31 percent of the total population of individuals under 18 in the US. This population is typically divided into three groups: 1) mild, i.e., having little adverse effect on activities of daily living, and accounting for 20 percent of the population; 2) moderate, i.e., ongoing limitations of daily activities, 9 percent of the population; and 3) severe, resulting in serious limitations of all activities, 2 percent of the population.

Partners In The
Medical Home Project

The Medical Home

The American Academy of Pediatrics (AAP), the federal agency Maternal Child Health Bureau (MCHB), and parent organizations recognized these problems and worked to establish guidelines for improving healthcare. The AAP and MCHB developed the concept of the Medical Home: services provided by the pediatrician's practice that are responsive to the special needs of these children and their families. The MCHB convened a conference at Egg Harbor attended by parents and professionals. The results of this conference were a set of criteria for the Medical Home based on parents' perspectives. The Medical Home is a concept of how pediatricians should provide the types and extent of services needed by CSHCN and their families. Overall, the AAP believes that the medical care of infants, children, and adolescents should be delivered or directed by well-trained physicians who are able to manage or facilitate all aspects of pediatric care (Ad Hoc Task Force on Definition of the Medical Home, 1992). Pediatric practices that qualify as a Medical Home are:

Accessible

- Practice is community based, located in proximity to primary residence of patients.
- Practice offers assistance with transition from fee-for-service to managed care through counseling, the services of an ombudsman, and patient education.
- Practice identifies assistance resources, information to families about public programs serving CSHCN, including state Medicaid programs, SSI-Assistance programs, Title V programs for CSHCN, state and private early intervention programs, special educations services, children's mental health programs, and private, community-based support services.

Continuous

- Practice provides medical support 24 hours a day, 7 days a week.

Comprehensive

- Practice provides primary, acute, extend-

continued on page 30

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ed, and family-services care.

- Health service includes medical, psychological, educational and behavioral help.
- Pediatrician has knowledge of the full range of child health problems.

Family-centered

- Pediatrician recognizes that parents are the child's primary source of support and experts on their own children.
- Pediatrician recognizes that families and professionals working together best shape practices and improve healthcare.

Coordinated

- Practice centralizes information from service providers in the practice's office.
- Pediatrician communicates effectively and collaborates on plan for child's care with all service providers.

Compassionate

- Pediatrician expresses concern for the well-being of the child and family.
- Pediatrician demonstrates cultural competence by respecting family's values, beliefs, and behaviors.
- Pediatrician actively listens to families and validates families' feelings.

Phoenix Pediatrics

The MCHB funded several projects in order to educate pediatricians and families about the concept of the Medical Home. One of the projects funded by MCHB in 1997 was the Phoenix Pediatrics, Ltd., Medical Home Project, Parents as Partners in the Medical Home. This project, funded through the Phoenix Pediatrics, Ltd., Practice, engaged a team of parents and professionals who collaborated in a series of research studies. The team's goal was to have parents systematically define the characteristics of the Medical Home, thereby outlining solutions to every day healthcare problems from the perspectives of families of CSHCN. (We will describe the work in upcoming issues of EP.)

Phoenix Pediatrics, Ltd., is a community-based medical practice, located in Phoenix, Arizona, that provides primary medical care to more than 20,000 children, including more than 2,600 CSHCN. Phoenix Pediatrics adopted the practices described in the Medical Home concept over 14 years ago under the auspices of Dr. David Hirsch and his associates. Dr. Hirsch is the medical director on the project. To provide the services outlined in the Medical Home, Phoenix Pediatrics created a "Clinical Care Coordinator" position, which is filled by Diana Frieberg, RN, BSN. Ms. Frieberg also serves on the Project team. Dr. Hirsch and Ms. Frieberg invited 20 parents and foster parents of CSHCN who are patients of Phoenix Pediatrics to work on the Project. The children have a wide range of problems, including asthma, seizure disorder, cerebral palsy, mental retardation, autism, traumatic brain injury, Down syndrome, spina bifida, hydrocephalus, and dwarfism. Most of the children have multiple, chronic, and sometimes life-threatening problems. Raising Special Kids, a grass-root organization of parents of children with disabilities in Arizona is a partner in the project. Judie Walker, professional development coordinator at RSK, brings expertise on working directly with families and parent coaching to the team.

Partners In The
Medical Home Project

Steering Committee. A committee of eleven parents and guardians of CSHCN and 10 health- and related-services professionals was established to represent the medical profession, managed care providers, community-based service agencies, hospitals, and parents. The Committee reviews the work of the research team and provides input from their organizations' perspectives, makes recommendations for project directions, and helps to disseminate the products produced by the Project.

The Role of the Parent-Professional Research Team. In this project the parents of children with special healthcare needs are included as active members of the research team, and, therefore, have a direct impact on the importance of the questions asked, the integrity of measures used, and the validity of the interpretation of results. The research model reduces the time to disseminate the results to families because the information has already been tested for the usefulness to families on an ongoing basis. Parents find participation de-mystifies the scientific process and teaches effective problem- solving strategies. For the parents, participation in the research process was a means of "beginning to know" rather than just "hoping" that positive changes can come about. By involving families who are most likely to be affected and have the most to gain from the results, we identify concrete, usable remedies that families find appropriate and feasible—remedies that fit in day-to-day family living. Working in a small group, with parents and professionals sharing responsibility and helping one another, the group has become a nurturing unit.

Parents as Partners in the Medical Home Project goals

The Parents as Partners Project was funded by MCHRB to improve the health status of CSHCN by making parents more effective collaborators with the pediatric practice. We did this by systematically identifying effective practices within the Medical Home. One of the criteria the team researched was communication. Research in this area has been concentrated on physicians' skills in communicating with parents. In the Parents as Partners project, the research team directed its attention to developing parents' communication skills, and defining effective strategies parents can use to communicate with healthcare providers. As part of this effort, parents tape-recorded and analyzed their communication strategies in their child's visits to pediatricians' and specialists' offices. We will describe the skills this team of experienced parents developed to navigate doctors' offices. The research team also developed a second method for improving parents' communication skills. The Children's Health Status Assessment (CHSA) is a portable medical record and Daily Planner that has parents collecting data on a daily basis to monitor changes in their child's health status. The goal of the communication studies is to help parents communicate more effectively (i.e., learn medical lingo, identify problems early, have an ongoing record of health episodes). Parents use the CHSA to track events that might trigger health changes and the consequences of treatment across time. In addition, parents keep track of the cost to the family of related activities and resources needed to support the child. We will describe how parents use the CHSA to monitor changes in their child's health, communicate with physicians and others about their child's health, and keep track of out-of-pocket costs of healthcare.

A second area covered in the upcoming series is the accessibility of health care facilities for CSHCN. Although the 10-year-old Americans with Disabilities Act (ADA) specifies how buildings must accommodate adults, families of CSHCN have some special needs not included in the ADA. The parent research team defined their needs in physical settings and rated the healthcare facilities that serve their children. We will share the Physical Environment Survey form used by parents to evaluate healthcare facilities.

Third, because CSHCN are complex and rare, parents have to seek out doctors who are experienced and willing to work with their children. The research team developed a set of criteria that parents of CSHCN can use in selecting a pediatrician. The criteria have been put into survey format other parents can use to select physicians and that physicians can use to evaluate their practice. Many "horror" stories made it clear that hospitals also are not necessarily prepared to meet the needs of families and CSHCN. The research team developed the Family-Centered Patient's Bill of Rights, a set of standards for providing services to CSHCN and their families during hospital stays. The Bill of Rights was put into survey form so that hospitals can use it to establish policies and services, train staff, and evaluate services. Parents can use it to understand and access good healthcare for their children during hospital stays. ■

Karen Burstein, PhD, and Tanis Bryan, PhD, both of the University of Arizona, are Co-principal Investigators for the Medical Home Project Team. As a parent of a CSHCN and former CEO of a children's rehabilitation facility, Dr. Burstein brings expertise on the problems of families and children as well as research design to the team. Dr. Bryan brings extensive knowledge and experience in conducting community-based investigators to the team.

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Circle #20

GOOAAAAAL! BALL

A unique sport that mixes purpose with fun

by David Chamalian

According to the U.S. Association of Blind Athletes (USABA), an organization whose goal is to promote independence and ability through athletic competition, goalball is an entirely original sport designed to bring together people with limited or no vision, not only for an exciting sports activity, but for rehabilitative recreation as well. Using a specially modified ball and a volleyball-size court, goalball provides players with an action-packed, physical outlet for developing physical fitness, improving auditory and tactile skills, enhancing social skills, and gaining an understanding of the benefits of teamwork.

A player on defense must be able to hear the ball, block it from going past, and get set for an offensive maneuver.

Goalball was developed in the mid-1940s as a rehabilitative activity for veterans of WWII who had been blinded. By playing the game, the idea was to help these people develop new, necessary skills. It has since evolved not only into a widely popular international Paralympic event (See Editor's Note), but, with the help of a few simple equipment items and an available gymnasium, a fun, meaningful activity that invites the participation of people at any fitness level, their families, and the entire community.

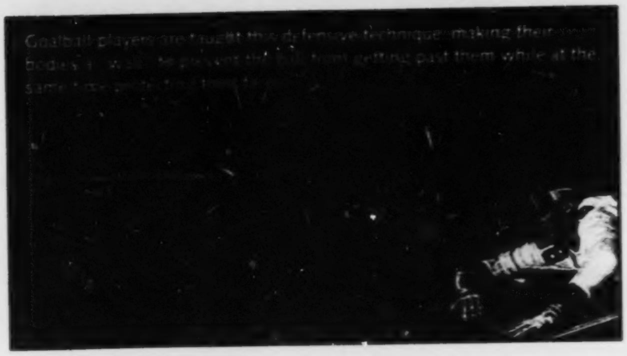
A novel game

The object of goalball is quite basic. It is played on an indoor gymnasium surface equal in size to a volleyball court. Two teams, each comprising three players who are required to remain in their designated areas, exchange turns in rolling the goalball, in a bowling motion (balls thrown in the air result in penalty), toward one another's endline, or goal. The defense, consisting of a center and two wings, must communicate to pinpoint the speed and location of the incoming ball and attempt to block it from getting past them and into the goal. Offensive skill lies in strategically placing the ball either between or beyond the reach of the waiting defense within the narrow eight-second time limit to avoid penalty. Whichever team has the most goals when the time expires wins the match. (Matches run in two seven-minute halves, with a three-minute halftime for switching sides.)

> "Kids of all physical ability can play goalball, and we want kids to have physical contact...Goalball gives them the opportunity to experience the physical contact they want and need."

The only sport developed specifically for people with visual impairments—not simply modified from a sport known to sighted athletes—goalball is tailored to suit the special needs of its players. Perhaps the most novel piece of equipment used in the sport is the ball itself. Goalball players must rely heavily on their auditory skills. Therefore, the ball used is specially designed with four bells inside that allow the players to hear it coming. Once they determine where the ball is coming from and how fast it is approaching, the defensive players position themselves within their designated areas, usually by sliding and laying fully outstretched, and block the ball from reaching their endline. Four small holes on either end of the goalball, which are designed to make the jingle of the bells inside more pronounced, make locating the ball even easier for the defense. (Goalballs are somewhat hard and textured and are slightly larger in size than a men's basketball.)

Equally unique about goalball is an accessory every goalball player is required to wear: a blindfold. Because the game is played by a mix of players with different visual abilities—that is, some may be totally blind and others may have low vision—the blindfold serves as an equalizer to any advantage those with some vision would otherwise have. Today, many players are using ski goggles with the lenses blackened out because they are less irritating to the eyes than standard blindfolds.



Goalball players are taught this defensive technique, making their [illegible] bodies [illegible] prevent the ball from getting past them while at the same time [illegible]

Proper positioning and orientation comprise two of goalball's essential strategies. How do blindfolded goalball players know which way they are facing, and how do they keep from straying out of position? The solution lies in the player's use of his tactile skills. Besides reliance on their auditory skills to gain orientation, people with limited or no vision need to count just as heavily on their tactile abilities. Each team's "team" and "player" areas, along with the court boundaries, are clearly marked with a double layer of tape, which may vary in type and thickness. The USABA recommends using either rough traffic tape (if available) or placing a rope or cord beneath either masking or gym mat tape. Duct tape may also be used, but it is recommended that a non-stick tape be used underneath to prevent ripping up varnish or painted lines on the floor.

More than a sport

At the highest levels of play, goalball is as much a cerebral game as it is physical. Aside from the lurching, sliding, blocking, and hand-ear coordination that are necessary, proper positioning, teamwork, good orientation, and concentration are also among the key skills any goalball player needs to succeed. For players, learning and developing these skills is not only for use on the court, but for use in life as well.

Jeni Armbruster, 25, plays goalball for the US national team and ranks among the best goalball players in America. The sport has allowed her to realize a dream. Once an aspiring basketball player and active in team sports all her life, Jeni did not discover goalball until she began to lose her vision in high school. As she learned the game, she soon realized how playing the game would help her adjust to her new visual impairment and help her stay focused on her goal of becoming a top athlete. "When I realized that basketball was an impossible career choice, I turned to goalball because it was a physical, team sport, which is something I had always been involved with and loved. But I needed to redirect my goals to another sport when I lost my sight; I needed some help with emotional and mental focus and goalball provided me with that." She credits much of her success with the game to the support of her friends and family. "My whole family has helped with my goalball experience. My dad became a coach, my sister kept score at my games, and my mom was the team 'mom'."

Along with the self-esteem boost, Jeni explains how goalball provides both recreation and a forum to connect with other people who have similar visual disabilities. "Goalball is a sport that allows you to have fun and gives you an opportunity to bond with others with blindness or visual impairments. You find out how they are doing in their lives and in their jobs, how they are living with their disability. You find out how they solve the problems they get stuck in, and you get to meet other people out there who are just like you."

Teamwork, says Jeni, is the most rewarding benefit of goalball. "The best thing about the game is learning to rely on your team and having them rely on you. You learn a great deal about teamwork and the camaraderie that goes with it."

According to USABA Assistant Executive Director Mark Lucas, goalball is a source of ideal physical activity. "Along with the team sport aspect, goalball gives players a physical and cardiovascular workout while building their hand-ear coordination." Admitting that participation in the game can come with its share of "bumps and bruises," Mr. Lucas stresses that goalball is safe and injuries are rare. "Kids of all physical ability can play goalball, and we want kids to have physical contact; they want it themselves. We don't want injuries, but if these kids were sighted they would be getting physical in other sports. Goalball gives them the opportunity to experience the physical contact they want and need."

The sport can also serve to fill the recreational voids that may exist both at home and in public schools' physical education programs for young people with visual impairments. "Kids who have disabilities are held back for many reasons," continues Mr. Lucas. "Many PE teachers, and even parents, don't know how to include youngsters with disabilities in physical education." Goalball is an activity that can help change that. ■

[illegible] mix up the speed of their deliveries to try to confuse [illegible] defense.

***EDITOR'S NOTE:** There is often some confusion surrounding the difference between the Paralympics and the Special Olympics. Only people with mental retardation (present before the age of 18) are eligible for the Special Olympics; while only people with physical disabilities, regardless of age, are eligible to compete in the Paralympics. See EP's article on the Paralympics in an upcoming issue.*

To learn more about goalball, request information on how to start a local program, or find out about the next scheduled clinic in your area, contact Mark Lucas:

The U.S. Association of Blind Athletes
Phone: (719) 630-0422
Fax: (719) 630-0616
Web site: http://www.usaba.org

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A Disabilities Conference for Everyone

by David Chamalian

EP's upcoming conference, the First Annual World Congress & Exposition on Disabilities (November 10-12, 2000) in Atlanta, GA, promises to deliver a broad scope of information, strategies, ideas, and information. A range of presenters, such as parents of people with disabilities, representatives of major advocacy groups, and professionals who are leaders in their fields, including education, healthcare, and related services, will share their perspectives. The presentations are broken down into three separate tracks:

The Medical Track

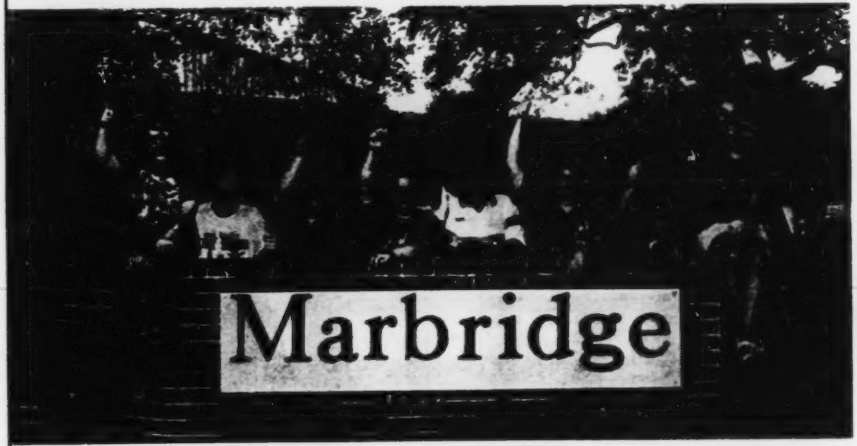
- **The Medical Home** *Speakers: David Hirsch, MD, MS, FAAP; Philip R. Ziring, MD; Karen Burstein, PhD; Tanis Bryan, PhD*—A concept which promotes a cooperative effort among the parents of a child with a disability and all related professionals to create more responsive, family-centered care (see related article in this issue).
- **Newborn Screening, Parts I and II** *Speakers: Edwin W. Naylor, PhD; Charles R. Roe, MD; Lawrence Sweetman, PhD*—Screening of newborns for a variety of conditions, though still uncommon, is possible in some situations: inborn errors of metabolism and hearing. Discussion will cover patient and physician awareness of testing; availability of testing; referral and treatments; costs and reimbursement; and more. (See part I of EP's three-part series on newborn screening beginning this month.)

The Education Track

- **Transitioning** *Speakers: George Jesien, PhD; Teresa A. Grossi, PhD; David M. Mank, PhD*—Making the transition from school to the work environment: an overview of critical issues for the individual, the educational institution, and the workplace; legislative mandates and the ADA; and resources for those who need assistance.
- **IDEA '97 and IEPs** *Speakers: Deb Kunz, Executive Director, Family T.I.E.S.; Dixie Jordan, the PACER Center; Bridget Via, Family Voices; Kathy Boundy, JD, Director, Center for Law and Education; Matthew D. Cohen, JD*—The implementation of IDEA '97 and a discussion on the development process of IEPs.

Family and Direct Support Professional Track

- **Life Needs and Estate Planning** *Speakers: Nadine O. Vogel, MBA; David M. Harmon, MSW, MBA, CLU, ChFC* —Information on the long-term financial care of children with disabilities, including wills, trusts, guardianship and other related topics.
- **Family Caregiver Burnout** *Speakers: Suzanne Mintz, Founder, National Family Caregivers Association; Rick Rader, MD*—An examination of the needs of a caregiver: recognition of burnout; short-term remedies; self care; support groups; long-term solutions; sources and resources. (See this month's article "Caring for the Caregiver" by Suzanne Mintz.) ■



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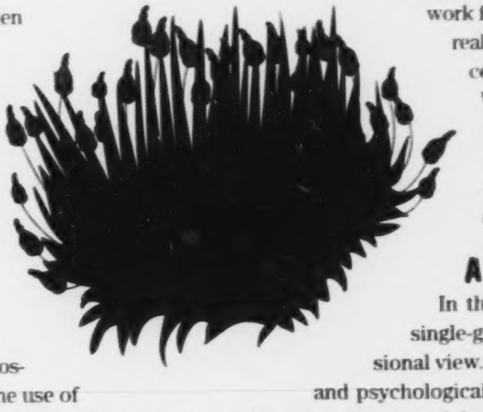
There Is ALWAYS an Alternative

by Maxwell J. Schleifer, PhD

The past decade has seen a rise in treatment approaches that are called "alternative" therapies or medicine. Many of them involve "natural" medicines containing a variety of plant derivatives. There has also been a parallel rebellion against the use of the ever-growing cornucopia of "approved" pharmaceuticals. Some of these natural remedies for specific disorders have been with us for a long time. Others are treatments that have been proposed by parents when physicians have told them there is no hope for their child. Some history and context of current practice may be helpful for parents as they consider "alternative" approaches.

NEW THERAPIES—NOTHING NEW

There has always been great interest in the natural medicines from the earliest days of our country. When Merriwether Lewis was preparing his expedition, he spent a month with Dr. Benjamin Rush of Philadelphia, one of the great pioneers of medicine in America. Dr. Rush theorized about disorders the travelers might encounter on their journey and provided Lewis with plants and herbs from South America to use as remedies. He also asked Lewis to keep track of the plants that the native peoples were using.



At the turn of the last century, there were a number of homeopathic medical schools and hospitals in our country. They were committed to the use of natural plants and herbs in treatment. Few of these schools now remain. The scientific approaches to developing medicine tended to obscure the value of the natural approaches, but they have never really disappeared. Many pharmaceutical companies are now devoting significant parts of their research budgets to identify which ingredients in plants have therapeutic value. The problems in purchasing these natural medicines are that the manufacturers are not regulated and the buyer cannot depend on consistency, purity, or dosage strength between brands and even batches of the same brand. Further, it is often difficult to know how these products will interact with the many medicines that children with disabilities often take. In many ways there are no real "new" treatment perspectives.

NOTHING WORKS FOR EVERYONE

Although holistic means considering everything that affects a person's body, it has come to represent strategies involving the psychological and social aspects of life as well. New treatment approaches have also come from arenas outside of "Western" medicine. For many years, parents and professionals have described new treatment approaches that they claim have worked when nothing else has. These have been effective for some children but not others. I also know that even the most effective "mainstream" therapies do not work for all children. Parents are usually more realistic about a treatment's chances of success than professionals believe them to be. We professionals should all respect parents as allies in the treatment of their children, but only time and experience allow us to truly appreciate their wisdom and insight.

A CHANGING VIEW

In the early 1900s, medicine went from a single-germ theory of disease to a multidimensional view. It was assumed that biological, social, and psychological factors contributed to the onset and course of an illness, and that each factor had an impact on the others. An illness mainly caused by biological factors affected an individual's interpersonal relationships and his or her self-image. However, even today, various specialists continue to focus on their own areas of interest and ignore or pay lip service to the other factors.

A good example of a multidimensional view in treating illness is embodied by the Framingham Heart Study. It was the first major

continued on page 38

Johnny, 51 lbs. and 48" tall in the Columbia Car Seat

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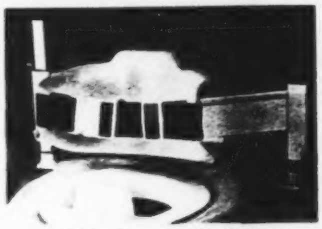

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Circle #23

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Many pharmaceutical companies are now devoting significant parts of their research budgets to identify which ingredients in plants have therapeutic value.

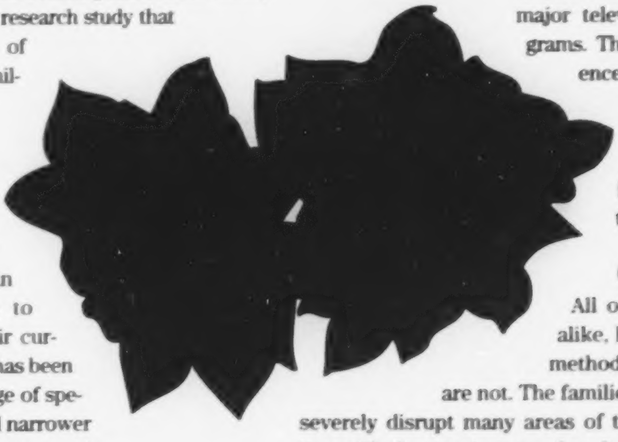
continued from page 36

study that provided a comprehensive examination of each dimension of heart disease and offered a total rehabilitation program. The researchers identified cholesterol as the major biological factor to be controlled in the prevention of heart disease. They also included the role of relaxation and physical exercise. The study recognized how personality type and social environment played a significant role in heart attacks and, therefore, also required attention. Soon, there was research on every major disease using the Framingham model. Later, Arthur Mutter and I performed the first research study that examined and demonstrated the role of psychological and social factors in children's illness.

ADVANCES IN MEDICINE, BUT NOT IN CARE

For a period of time, healthcare professionals actively considered all factors in making plans for individuals in their care. Medical schools began to include human ecology as part of their curriculum. This is the holistic model that has been "rediscovered." Then we entered the age of specialization, which led to a narrower and narrower focus, so much so that some practitioners see only their area of specialization and not the whole person. We have seen major advances in pharmaceutical products aimed at specific diseases. The power of the medications and the immense publicity they garner lead people to believe that these "magic bullets" are sufficient to deal with the problem.

We have also entered the age of third-party insurance. Most medical care is covered by an employer's insurance. A family's coverage is now determined mainly by the place of employment and its coverage. In competing for customers, insurance companies began lowering their prices. As they began to lose money, carriers have systematically limited what they will cover. This has given rise to conflict for members of an individual's treatment team who deal with the psychological and social factors, even for psychiatric illnesses, often with negative consequences. Finally, insurance policies will not cover treatments that are in the "experimental" phase—often the last bastion for children with untreatable illness.



WHERE DO YOU GO?

A major issue for families with children with major medical problems—those that have been refractory to all usual approaches—is that the medical establishment has given up hope. The family often recognizes the medical team's sense of defeat before the team does. However, families cannot be expected to give up and not search for new treatments or programs. They are then most likely to consider or use treatments that do not meet the standards that Western medicine uses to prove that a method is effective. There has always been a "treatment underground" where information about alternative therapies has existed. From time immemorial we have read about "miracle" programs in other countries, such as the Far East. Some of those treatments, like acupuncture, are now part of our treatment array and supported by insurance coverage.

We have always known about the folk cures brought by people emigrating to this country from every region of the world. Even now I hear from clients who have gone back to their country of origin and found "cures" for medical problems that were "untreatable" here. In recent years there have been a plethora of books describing alternative therapy approaches to almost every illness—chronic as well as acute. The leaders have been interviewed on major television networks and radio programs. They are often included at conferences. Knowledge of these "alternative" approaches has expanded because of the wider dissemination of information that is now available, especially through the Internet.

CHOOSE CAREFULLY

All of us, professionals and families alike, have difficulty sorting out which methods are truly effective and which are not. The families of children with problems that severely disrupt many areas of their functioning, and are sometimes life threatening are often faced with trying to choose among conflicting professional opinions. One solution for families may be to turn to the parent and professional associations involved in the child's illness. Many of the organizations devoted to specific disabilities report regularly on new or alternative treatments and give their opinions based on research and experiences of others. EP also features the views of the professional associations when they have sufficient research evidence.

We hope parents will consider new ideas in treatment, but they should involve the child's primary physician about the various treatment approaches they have either read or heard about. Parents should not be discouraged if these ideas are not received with great enthusiasm, particularly if they are considered alternative therapies. At the same time, parents need to be cautious, making sure their child's physician follows up on the child whenever new approaches are used. A thorough, ongoing evaluation of any treatment method is essential. It is the child's ultimate protection. ■

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Circle #47

Bonfire of Love

How one family, through faith and persistence, found a solution to their son's drooling problem.

by Ronnie Wells

Austin saved some of his bandannas for his dog Ellie. After being fitted with an intra-oral drooling appliance, he no longer has a use for them.

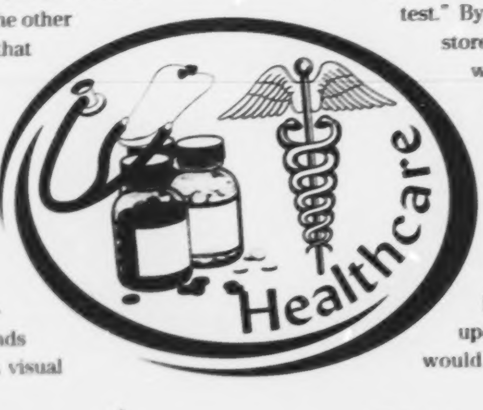
My adorable son Austin, 14, has an unfortunate problem: drooling. This can be a "social bummer" that words cannot begin to express. I do not understand why people just will not look past a little drool. Well, okay, maybe a lot of drool. Maybe even sometimes it hung from his lower lip like a long spider web. During the winter, we had seen this area freeze! Not a pleasant situation. This has been a difficult obstacle to overcome for Austin.

Austin has cerebral palsy, a seizure disorder (controlled with medication), and bilateral optic atrophy which causes a visual impairment. The challenges that accompany these disorders are many. We had been told by professionals: "Your child needs to use a wheelchair to get around;" "Your child is not going to be able to: read normal size print, drive a car, develop at the same rate as his peers," etc. In time, we learned to deal with all of that. Austin is fortunate in many ways because the other children seemed to be able to deal with all that stuff, too—everything but the drool.

No easy way

We always tried to teach Austin to be aware of his body and its functions. Besides reminding him to swallow and to wipe his chin, occasionally we would set up a mirror at the table so he could practice by monitoring himself while eating. Austin also wore colorful wristbands made of terry cloth that could serve as a visual reminder and that he could also use to wipe his mouth if he didn't have a napkin nearby. I also decided to buy colored bandannas for him to wear around his neck that would coordinate with all his clothes, thinking that this might help protect the clothes and hide any staining. My husband and I became very selective when purchasing clothes for Austin. We would give it the "drool test." By hiding behind a rack of clothes in the store, using a spray bottle from my purse, we would add a few drops of moisture to the garment; and quickly check to see how the garment might look after being worn by Austin.

White and black, thin cotton always worked best. Still, Austin was asked a million times a day to swallow. "Wipe your chin Austin!" "Austin you're drooling...gross!" His friends at school took it upon themselves to be the drool cops. Some would go as far as to wipe his chin for him.



Others just exclaimed their displeasure at his seeming lack of concern. The color coordinated bandannas, even the designer ones, did not seem to make a difference.

I became very bitter. The younger children seemed to be more accepting of Austin's problem. I knew as he got older and moved up in school, this would become more of a social barrier than it had been at a younger age.

Finding a solution became my mission. A journey, not only in the physical sense but a spiritual quest as well. I prayed. I read. I took many long walks in the pasture. I attempted to "make a deal" with God. I had trusted Him with so many other aspects of my life, but not this. I prayed, "Lord, this is a mountain that I cannot move. Please help!" Soon, He did just that.

A new horizon

When our family moved to another city in the summer of 1996, it would be a chance for a new beginning. Austin would be attending a new school and I would have the opportunity to find a new team of doctors, and perhaps find some fresh ideas in the new surroundings.

We were referred to the Scottish Rite hospital in Dallas. We made an appointment with a neurologist. "What can we do about the drooling?" I asked. The doctor that we saw seemed to have a lot of experience with pre-adolescent children with

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The Wells Family (right to left), Ronnie, Dylan, 2, Austin, Patrick, and Ellie, never gave up hope in their search to find a solution to Austin's drooling problem.

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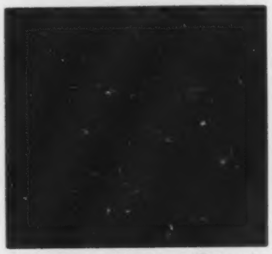
The Intra-Oral Drooling Appliance



Patients need to be sufficiently cognitively aware so they can follow directions to swallow on command in order to be candidates for this appliance.

As Austin Wells and his family found out by their experience, the impact drooling has is more than physical—it can effect how others will perceive the person who has the problem. Dr. Suzi Seale, director of Dental Service the Texas Scottish Rite Hospital for Children in Dallas, notes, "Drooling in and of itself does no harm to the teeth and the biggest issues related to the importance of controlling drooling relate to social acceptance of the child."

Though the use of the intra-oral drooling appliance, provided through the Dental Service, helped stop the drooling for Austin, it is not for everyone. Dr. Seale emphasizes, "Patients need to be sufficiently cognitively aware so they can follow directions to swallow on command in order to be candidates for this appliance." Fitting into the upper part of the mouth, the intra-oral drooling device works by stimulating a response by the tongue which aids in swallowing. A similar device has been used by clinicians in other institutions. Dr. Seale describes the device used at Scottish Rite:

"The drooling appliance is very similar to an orthodontic retainer in its design and fabrication. It is an intra-oral appliance which is constructed of dental acrylic with wire retainers. A bead is placed in the palate and is attached so that it is free to rotate as the tongue brushes it. The tongue seeks and manipulates the bead, and in doing so, facilitates swallowing."

In order for the device to be most effective, it must be tailored specifically to each individual, matching the size and shape of the mouth. "An impression must be made of the upper dental

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cerebral palsy.

He seemed to appreciate our concerns. After the usual barrage of questions and answers, we were handed a prescription. We were assured that this may help with the drooling and we were sent on our way. I was so grateful and gave thanks to God.

Soon after we started on the drug, I did notice some improvement. I was very hopeful this would make a difference for Austin.

He started at a new school. Children seemed to love him right away. Even though the drug seemed to help somewhat, the side effects had us concerned: delayed urination, the feeling of "having to go" and "not being able to" became a problem. He was also sensitive to the heat. His face would become red and blotchy. The side effects continued and so did the drooling.

By the time Austin was in middle school, the children were less accepting of the drooling and his eating habits. "Yeah, Austin is a pretty cool kid most of the time, but does he drool because he's retarded? " Austin continued to develop a strong self image despite all this. We always taught him that appearances are not everything. It is not what's on the outside that counts most in life, but what's on the inside—what you give to others.

It broke my heart to see this going on. We made an effort to educate everyone around Austin so that if they understood why he drooled, they might be more compassionate. Some of his friendships became strained, however, and in one instance a 'friendship' was lost. I continued looking for the answer. I searched the Internet, I frequented seminars, I grilled other parents in simular situations. I was constantly reminded of the desperation shared by numerous parents with similar

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arch so that a model of the patient's mouth can be made," explains Dr. Seale. "This is so that the appliance can be fabricated to exactly fit the individual patient's mouth. Therefore, the patient must be sufficiently cooperative to have this impression made."

The Hospital's clinic is limited in its ability to provide this intervention to children who are not currently patients, but will provide more information upon request. For more information on this device, contact: The Dental Clinic at Texas Scottish Rite Hospital for Children, Dallas, TX Telephone: (214) 559-5000.

The drooling appliance is very similar to an orthodontic retainer. A bead is placed in the palate and rotates as the tongue brushes it. The tongue seeks and manipulates it which facilitates swallowing.

circumstances. Our family has a very strong faith. I prayed to God to please have mercy, either open a door or give me a heart of acceptance.

Late in the fall of 1998, I found out that Scottish Rite Hospital had a dental clinic and got a referral. At our appointment, everyone was extremely caring and supportive. They told me that Austin might be a candidate for a new device that could help in controlling the saliva flow. This I felt was too good to be true. But we would try anything at this point.

After a brief screening process, the clinic determined that Austin was a candidate for this mouth appliance. (See sidebar for details.) We learned that the appliance would fit somewhat like a upper retainer, which had a small bead attached to the back that would stimulate a swallowing reflex. An impression was taken of his bite so that the device could be made to the shape of his mouth. It would take a few weeks for it to be completed. If the device did not cause a gag reflex in Austin, this could be what we were looking for. We were cautiously optimistic.

Never lose sight of what you want

We returned to the clinic weeks later to try out the mouth appliance. The moment of truth came as the doctor inserted the tiny plastic and wire device, and to our relief Austin had minimal gag response. Moments later the doctor and I noticed that he was swallowing. The drooling

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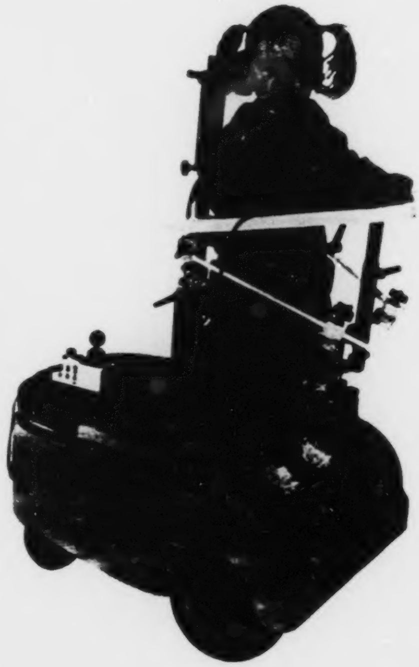

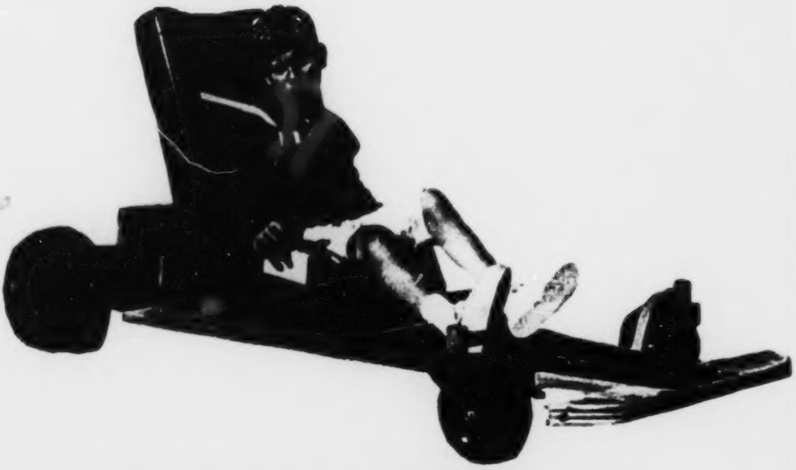

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Circle #41

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stopped almost immediately. I had never seen my son swallow without being told to do so. I find myself staring from time to time in total amazement. The look on my son's face that day when he said, "I don't drool anymore," could absolutely launch a thousand rocketships to the moon! I could not wait to get to the nearest phone and call my husband and share the great news. Looking back, the irony of all this is I thought I had looked everywhere—except in my own "backyard." The "moral" is that you should never lose sight of what you want.

Some time has passed since Austin received his retainer and we are continuing to see improvements in many areas of his life. I had lunch with him at school not long after he had the device, and was delighted to see some new and curious kids hanging around. One morning, as he was headed out the door in his wheelchair to catch the schoolbus, I was scurrying about gathering all his school stuff. I yelled, "Wait Austin, you forgot your bandannas." With a full grin from ear to ear he replied, "Mom, I don't need 'em anymore!" No words can express how this has made me feel, but more important, what this has done for Austin. God knows—He had His merciful hands all over this and I am truly thankful.

I am also deeply grateful to the team of specialists at the Hospital. Because of their dedication to the children and their parents, this opportunity is now available to many people in need.

We planned a camping trip for the coming Thanksgiving holiday. We would have a big bonfire. Austin and I agreed we should toss those bandannas into the bonfire. Austin laughed, and came up with another suggestion, "Nah... maybe Ellie the dog will want to wear them!" ■

Healthcare

The Wells family, Patrick, Ronnie, Austin, Dylan, and Ellie the dog, make their home in Texas.

This article is adapted from one which appeared in the Winter 2000, Volume 5, Number 1 edition of SEE/HEAR newsletter published by Texas School for the Blind & Visually Impaired (TSBVI) and Texas Commission for the Blind. The original article will also be available soon in Spanish on the TSBVI web site at: http://www.tsbvi.edu in the "Ver/Oir" archives.

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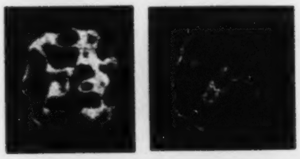

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Sending Out a Message of HOPE

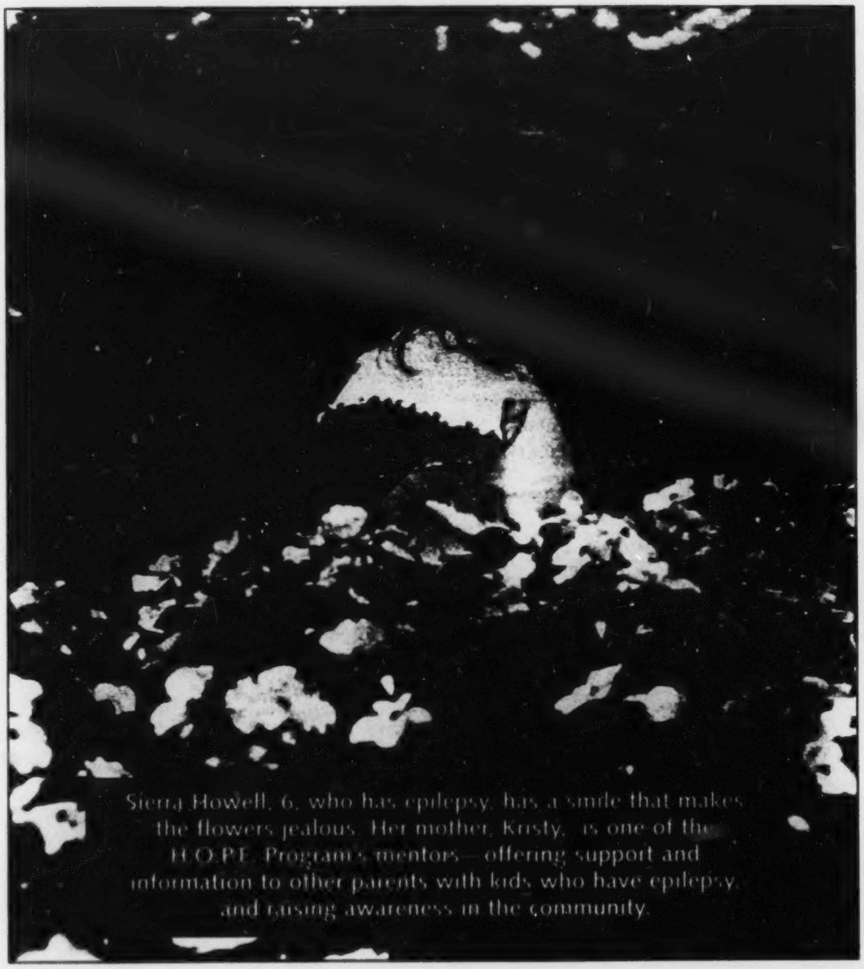
People with epilepsy get support and the benefits of community awareness from The H.O.P.E. Mentoring Program™

Healthcare

Nowhere to turn

Ann Donnelly, of Florida, had a lot to cope with. Not long after learning her son Sean had cerebral palsy, Ann found out he also had epilepsy. Her son's doctors provided as much information as they could on epilepsy, and as a medical transcriptionist, Ann had professional knowledge which she augmented by reading textbooks and doing extensive research on epilepsy. Still, something was missing; she had nowhere to turn for help with the emotional issues and daily living issues. She was unable to find a support group or anyone else with whom to share her experiences.

That was twenty years ago. Today Ann serves as a mentor for The H.O.P.E. (Helping Other People with Epilepsy) Mentoring Program™, sharing her first-hand knowledge with other parents and the community so that others do not go through the isolation she did. The H.O.P.E Program is an initiative designed to train people affected by epilepsy to help others learn more about the disorder. The program, part of the Epilepsy Foundation and supported by UCB Pharma, Inc., is the first of its kind to send people affected by epilepsy out into the community to educate others about epilepsy. "By connecting people with epilepsy to mentors who have lived with the disorder, H.O.P.E. tries to alleviate loneliness and provide practical advice on day to day coping. In addition, since many people still do not understand epilepsy, the H.O.P.E. mentors can shed some light on the mysteries that often surround this disorder," says Martha Morell, MD, pro-



Sierra Howell, 6, who has epilepsy, has a smile that makes the flowers jealous. Her mother, Kristy, is one of the H.O.P.E. Program's mentors—offering support and information to other parents with kids who have epilepsy, and raising awareness in the community.

BY KERRY PIANOFORTE

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fessor of clinical neurology at Columbia University College of Physicians & Surgeons and director of the Comprehensive Epilepsy Center, Columbia Presbyterian Medical Center of New York-Presbyterian Hospital. Dr. Morell is one of the developers of the H.O.P.E. Program.

Teaching from experience

Mentors undergo a three day training session and receive certification through the national program. They start working through local Epilepsy Foundation affiliates to coordinate local meetings, presentations, and other educational events. According to Patricia Dean, a nurse practitioner and member of the National Epilepsy Foundation Board of Directors who was involved in the training of the mentors, the program benefits the mentors as well as the audience. "It's helpful to hear about epilepsy from someone who has personal experience. It's a good experience for the mentors. They can take their knowledge and help someone else with it. It's empowering."

Epilepsy Foundation Executive Vice President, Cindy Brownstein, feels that "The Epilepsy Foundation's H.O.P.E. program is a wonderful example of volunteers working in their communities to educate people about epilepsy. It is our hope that this dedicated group of volunteers can touch thousands of people with epilepsy and their families and at the same time reach the public to help to eradicate the stigma associated with epilepsy. "

H.O.P.E. Mentors are generally people whose lives are touched by epilepsy, such as parents, caregivers, or adults who have the disorder, and are recommended by local healthcare professionals and Epilepsy Foundation affiliates. When Ann was approached by her local Epilepsy Foundation to become involved in H.O.P.E., she was excited to be able to help, especially with all the support she could offer parents who have a child who is newly diagnosed. "Because we have been dealing with this for such a long time we have a lot of tips and advice on everyday living," she explains.

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Putting H.O.P.E. Into the Community

The mentors are sent out into the community to educate children, parents, teachers, and other professionals about epilepsy. The core curriculum used by H.O.P.E. mentors includes a set of standardized teaching materials—brochures, slides, and videos—developed in collaboration with medical professionals and the Epilepsy Foundation Professional Advisory Board. The three pre-designed programs that H.O.P.E. mentors can choose from to present at scheduled events are:

- "What is Epilepsy" - definition, diagnosis, treatment options, and seizure first aid
- "The Impact of Epilepsy" - effects of epilepsy on patients and family, lifestyle issues and coping skills
- "Advocacy and Self-Management" - taking responsibility for managing your life and workplace-related issues. In addition, information and slide presentations developed for these programs can be further tailored to address the needs of the audience in attendance.

H.O.P.E. MENTORING PROGRAM™ ACTIVITIES

The core curriculum used by H.O.P.E mentors includes a set of standardized teaching materials geared toward a wide range of audiences, including people with epilepsy, medical professionals, and members of the community.

Learning opportunities include:

- Lectures and small group discussions
- Health fairs
- Support groups
- One-on-one consultations with newly diagnosed patients and their caregivers
- Web chat rooms
- Teleconferences

Medical education events for physicians and healthcare professionals include:

- Lectures and discussions for medical interns and residents
- Presentations to managed care professionals
- Physician training sessions
- Hands-on workshops

Local community education programs include:

- Seminars for corporate human resource directors and employees
- Presentations to teachers and staff at local schools and day care centers
- Training sessions for employers and personnel at local businesses and chain retail outlets
- Lectures for church groups and local chapters of national organizations (PTA, Elks Club, Jaycees)

To schedule a presentation or event through The H.O.P.E. Mentoring Program™, call (877) HOPE-4-YOU, or visit the Epilepsy Foundation Web site at http://www.epilepsyfoundation.org.

The Epilepsy Foundation has also launched a new page within its Web site called "The Epilepsy Answer Place." The page is a resource that provides information about epilepsy for individuals who have the disorder, their families, and professionals. The information is divided by topic and by audience. Answer Place can be found on the home page of the Epilepsy Foundation's Web site.

Scott and Kerri Branson and their sons Luke and Zachary, who have cerebral palsy, live in Batavia, IL.

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Ann Donnelly speaks to a professional. As a mentor, Ann is finding help and support for her family, as they continue to search for answers to her son's epilepsy.

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"New parents don't know what the future holds." The mentors help parents in many ways. According to Ann, "It gives them more information about the disorder so they can accept and understand it. They are better prepared to cope."

Also part of Ann's goal as a mentor is to increase epilepsy awareness among those who provide services to the community such as emergency service providers, teachers and other school personnel, and shopping mall security personnel. With that training, they can be prepared to help someone having a seizure.

Ann and her family continue to grapple with epilepsy, as an exact cause for Sean's epilepsy has not yet been found and the 21-year-old still experiences seizures on a weekly basis. Through her efforts with the H.O.P.E. program, however, Ann has also found more support and help for her own family while making a difference for many others.

A personal perspective

Paul Dammann, of Florida, an oceanographer and a person who has epilepsy, is a mentor. When Paul was first diagnosed with epilepsy at the age of 16, he began to do as much research on the disorder as he could. He discovered a great deal of literature and articles in medical journals about epilepsy, but also found there was little practical information or advice on handling the disorder on a personal level.

Growing up with epilepsy, Paul did not have any support groups or networks of people to talk to or to turn to for advice. As an adult, Paul became involved as a H.O.P.E. mentor in order to help others in his community to understand and accept epilepsy. In particular, he hopes to improve conditions for people with epilepsy in the workplace by educating mangers and employees at local businesses. Paul explains, "The most important benefit of

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the program is that it gives people the ability to hear from a person who has lived with epilepsy. They can give a perspective that a doctor or a nurse does not have."

Lifting the shroud of misunderstanding

Kristy Howell, of Georgia, another H.O.P.E. mentor, will never forget how she and her husband felt when they learned that their then 21-month-old daughter, Sierra, had epilepsy. "It was a shock when we found out she had seizures. She looked like any other kid," says Kristy. They did not realize that the small changes they had previously begun to notice in their daughter's behavior—such as eye fluttering and a tendency to hold her head up to light—were all signs that she was having a seizure. Their shock turned to confusion after the diagnosis. They were having difficulty understanding the medical terminology and did not find anyone with practical experience in living with the disorder to answer their questions.

Kristy searched her area for a parent support group, which she thought might be able to help her. When she could not find any, Kristy decided to start her own. As a mentor, Kristy hopes that making people aware of epilepsy and educating them on the facts will remove "the stigma associated with epilepsy." Though she has already made many presentations on epilepsy to raise community awareness, now as a mentor, Kristy will put a special emphasis on working with school officials to teach them to recognize seizures. Among Kristy's other activities will be providing a consultation service to families with children who have just been diagnosed with epilepsy. Perhaps the most important part of Kristy's mission is to get the public to realize what she has learned through personal experience—that epilepsy should not be a barrier for those who must live with it. She reports that her daughter Sierra is an active 6-year-old who "keeps her mother on her toes and loves being a big sister to 3-year-old Crystal. She's doing great." Says Kristy, "People with epilepsy can achieve their dreams and not have to hide their disorder." ■

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TEENS Care About Their Care

According to a recent survey, as teenagers with disabilities mature, they become more vocal with their feelings and opinions, saying they want and need a greater voice in their own healthcare. "Adolescents Want Control of Their Healthcare" reports on the findings of the survey, in which teens with a disability indicated what they want to know in order to be participants in their care. The accompanying article, "Aid for Adolescents Who Want to Take Charge," highlights ideas about what young people need to learn to manage their care. Both articles are adapted from original pieces that appeared in the Spring 2000 issue of "Window on Wellness," a health and wellness publication for people with disabilities.

Adolescents Want Control of Their Healthcare

by Carol Igoe

What do teens and young adults with disabilities say about their health and health care? They say they want to be in charge!

Like all adolescents, these teens also want to find out who they are, cut the apron strings, belong to their own group and be independent. In the past, parents and health care professionals often felt that they had to keep this responsibility and protect their children and patients. They focused on the disability or long-term health condition and overlooked typical adolescent life tasks that all teens need to try to master.

Today, we are changing this attitude: we are recognizing that all teens have the right to envision and plan their futures. The new Individuals with Disabilities Education Act (IDEA) legislation for transition requires that special education students be taught about the legal rights and responsibilities that all American citizens receive when they reach age 18.

Among organizations that are important resources in the movement toward more independence in health management are:

- **PACER Center in Minneapolis** (see Resources box next page). For almost a decade, parents at the center have helped young people with disabilities and their families speak out for health.
- **Healthy and Ready to Work (HRTW) projects**. Funded by the federal Maternal and Child Health bureau, seven HRTW projects help states develop adolescent transition services that include health care. In Cincinnati, Ohio, for example, there is Career Connections for Students at Lighthouse Youth Services. The WISH project at Shriners' Hospital serves young people in Lexington, Kentucky. For the nearest HRTW project, call the Institute for Child Health Policy at (352) 392-5904.

Teens speak out

What does "taking charge of health care" mean for teens and young adults with disabilities? In 1997, the PACER Center surveyed young people aged 14 to 25 in Minnesota. They had chronic illness or sensory, physical, learning or cognitive disabilities. Young people said they want to know:

- How to pay for their healthcare;
- More about their disability or chronic illness;
- What can happen if their condition becomes worse.
- How to make an emergency plan if their condition does get worse;

Teens want adults to talk to them about their healthcare:

- They want someone to talk to about how to make their own medical decisions (less than 50 percent said they have someone to talk to).
- They want to meet someone with a similar disability who is working and living independently, who can be a mentor and guide.
- They want to be able to talk about health promotion and risk behaviors and concerns, such as:

1. Sexuality
2. Smoking
3. Alcohol and drugs
4. Feeling really angry or sad
5. Hurting oneself or being hurt by others
6. Family planning

- They want their medical providers to give them information about medical issues and their disability or chronic condition.

When Shriners' Hospitals surveyed adolescents and young adults in Florida, Kentucky, Utah, and Hawaii, the young people described two barriers to taking charge: their own fears and overprotection of their parents.

For these teens, healthcare includes health skills, such as:

- Taking medications;
- Having information about specialized resources;
- Gaining self-knowledge about their maturing bodies and about their long-term conditions; and
- Gradually taking over responsibility.

One participant said, "We have the same basic needs as anyone in this age group; however, we also have extra considerations and limits that may be placed on us as we work towards independence."

"For me, one of the hardest things during my teenage years was that I wanted to challenge and defy my parents, as many teenagers do. However, because I was physically dependent on them for my personal care, my desire for independence seemed thwarted. There are many other special problems you may encounter that add to the difficulty of this transitional age. For example, if your chronic illness or disability is severe, you or your parents may think it is futile to plan for the future. If your disability or chronic disease is hidden, it can seem easier to deny, hide or ignore the needs of your health."

Carol Igoe is a special educator, behavorial psychologist and family support specialist in the field of developmental disabilities. Ms. Igoe is also Program Director for the Ohio Healthly and Ready to Work Project, Career Connections for Students at Lighthouse Youth Services in Cincinnanti and a parent of a child with disabilities.

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Circle #43

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Aids for Adolescents Who Want to Take Charge

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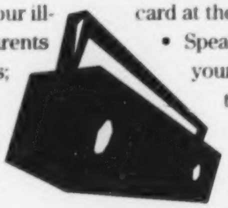


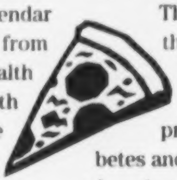
- Find out more information about your illness or disability: talk with your parents and doctor; get books and videos; meet others with your condition.
- Find out about your body: determine what you can do for yourself; what you need help to do; get sex education.
- Figure out your strong points: try school clubs, church groups, sports, and hobbies.
- Figure out which accommodations you need to learn and work: ask therapists, special education teachers, other people with your condition, or a vocational counselor.

Take Care of Your Health

- Learn to handle your medicine: use a medication box; contact the drugstore to fill your prescriptions; use your insurance card at the doctor's office.
- Speak up for yourself: remind your parents to let you talk to the doctor; plan ahead what to say; find a way to use a record book to share your health history.
- Make medical appointments: put together a list of your doctors and therapists and their phone numbers; explain your symptoms; use a calendar for appointments; access books from PACER such as Speak Up for Health and Workbook for Teens with Developmental Disabilities (see Resources box on previous page).
- Plan for adult medical services: get names and adult primary and specialty doctors; learn about health insurance and SSI (Supplemental Security Income).

Teens speak up, learn

Teens and young adults are finding their voices to speak for themselves, master their self care, even help their parents understand what they want for themselves. Teen talk groups provide a sounding board to give them insight, courage and strategies to make these changes. Teens are surfing the Web to find out about their conditions and to meet other teens. There are chat rooms, online connections for hospital patients, bulletin boards, and Web directories.



There are books for teens to help them understand their disability. There have been patient-education and self-management programs for some time for diabetes and asthma. Now self-management education extends to other conditions; for example, the book *Spinabilities: A Young*

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Circle #38

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Person's Guide to Spina Bifida (see Resources box at end of article).

Parents' role

How do teens with disabilities and chronic conditions learn to take charge of their health? Like all transitions from adolescence to adulthood, this is a process, not an event.

It is a process that is best begun by parents in early childhood, but it is never too late to start. It includes teaching children about their disability and talking about puberty and sexuality.

The process should gradually grant children an active role in their healthcare by supporting self care, helping them learn to talk to their doctors, developing their responsibility for making appointments, and planning with them to transfer to adult medical providers.

Historically parents and providers have focused on treatment and habilitation and overlooked typical childhood development. A life span, developmental approach helps parents support independence and loosen control. This approach emphasizes capability, experiential learning, autonomy and letting go. Parents who have had to live with health risks and other challenges their child has faced often find it difficult to allow typical adolescent risk-taking.

Here are two helpful resources for parents about the developmental approach to teaching their children self-management skills in healthcare:

- A free brochure called "Paving the Road to a Brighter Future" (see Resources box at end of article).
- The chapter called "The Impact of Chronic Illness and Disability on Adolescent Development," in *Speak up for Health: A Handbook for Parents* (see Resources).

Physicians' role

Physicians are key players in the process. Dr. Kathleen Charvat and Dawn Nebrig at Cincinnati Children's Hospital gave this description of the role of the physicians:

Visionary—Growing up is the goal.

Guide—Start anticipatory guidance before 12 years of age.

Teacher—Educate teens about their disability.

Coach—Build self-advocacy skills in your office.

Resource—Provide names of adult providers and discuss insurance coverage.

Cheerleader—Support families through the process.

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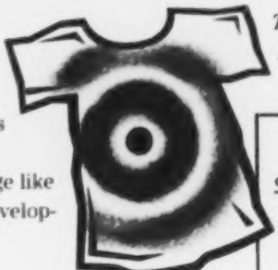
Physicians themselves report that this is a difficult shift. It is difficult to:

- Address chronic, even life threatening health conditions with adolescent patients
- Change the role of parents.
- Address a typical developmental change like puberty, when the disability affects development.
- Deal with the lack of adult providers.



It's worth it

Young adults who have achieved independence—with the support they need—say it is worth the struggle.

Nicole Robert, a young woman with muscular dystrophy, describes her achievement:

"Today I live in my own apartment. I have an attendant who provides me with the care I need to live independently. I make my own decisions about my healthcare, and I train the people who help with my healthcare treatments. With freedom comes responsibility, and like everyone else, my life has its share of challenges. However, owning my own life is worth any challenges I encounter along the way." ■

This article is adapted from a brochure called "Transition F'Acts," a publication of Career Connections.

Resources

Spinabilities: A Young Person's Guide to Spina Bifida is available through the EP Library: (800) 535-1910, Web site: http://www.eplibrary.com.

Transition F'Acts is developed by the Health Care work group of the Southwest Ohio Transition Roundtable 1999, with funds from the Ohio Developmental Disabilities Council.

Free copies of *Transition F'Acts* and *Paving the Road to a Brighter Future* are available by calling Lighthouse Youth Services, Inc., at: (513) 475-5500.

Speak Up for Health and *Workbook for Teens with Developmental Disabilities* can be ordered through the PACER Center.

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Circle #18

10

890

Caring For The Caregiver

Yes, I am a family caregiver

by Suzanne Mintz

> **By identifying myself as a family caregiver, part of a group, I am building recognition of what I do. I am saying I am not an isolated instance, an oddity of one. I am part of a group of people.**

Who am I? How do I define myself? How do you know me? These are heady questions—ones we ask ourselves all of our lives as we try to establish our identities and find a place for ourselves in the world.

I define myself in many ways, with my name. I am Suzanne Mintz, Suzi to those who knew me since childhood. Just by looking at me there are many things you can see that give you some idea of who and what I am. I am obviously female. I am Caucasian. I'm a brunette, and I am petite.

These are all part of my physical presence, the outer shell, your first impression. We define ourselves in other ways as well, by our professions, by our religion, by our ethnic background, by our hobbies. Each label carries with it a set of facts, images, statistics. Some of them we choose. Others we do not. The point is, who we are is the summation of many different facets of our life and the categories into which we fit, and they tell society something about us as well.

None of us likes to be stereotyped, but we don't like feeling all alone either. By identifying with a group, we gain some recognition. We fit in. We belong. We also gain knowledge about ourselves. I feel comfortable when I walk into a room full of women in their "middle years" because we share things in common. Our bodies are changing, and with that, our identities. I can talk to these other women and be validated. Because of research on women in their late 40s and early 50s, I can turn to a book and learn what else to expect. I can gather statistics, information, become as educated as I want about this facet of my life. Identifying as part of a group can be very beneficial.

Who am I? I am the sum of all of my labels—and then some. I am a wife, mother, daughter, Jew, Sherlock Holmes fan, fair-weather jogger. I am a type "A" personality. I am a writer. And yes! I am a family caregiver, too.

It is not the first way that I describe myself, but it is definitely part of who I am, and I believe it is a part that all of us in this role need to own—for our own sakes and for the common good.

Yes, I am a family caregiver! It is becoming a mantra for me, and I think it should for you as well.

By identifying myself as a family caregiver, part of a group, I am building recognition of what I do. I am saying I am not an isolated instance, an oddity of one. I am part of a group of people—in fact a very large group —with common issues, characteristics, needs and concerns. We caregivers so often fall into our own roles, just taking on tasks one after the other, as a matter of course, feeling feelings we are afraid to own. By giving a name to our situation we validate our experiences, and all of our feelings. We say to the world: Here I am. Look at me. Acknowledge me. Help me.

By identifying ourselves as family caregivers, we are in a position to fight for our rights, to begin to change the way society regards us, to start feeling better about our situation because we are identifying it for what it is: a painful job that we are so often asked to do alone, regardless of the physical, emotional, and financial costs.

For too many years I did not have a name for what had happened to my life when my husband Steven was diagnosed with multiple sclerosis. For too many years I was angry and unable to be comfortable with myself.

By identifying myself as a family caregiver, and by asking you to do the same, I no longer feel alone, angry or displaced. In fact, I feel strong and empowered. Armed with statistics and stories, I hold my head up high and reach out for help with dignity. I talk to the press and members of Congress. I meet with other groups whose issues converge with those of family caregivers and chart a course for change in our healthcare system. I feel okay about my pain and understand my frustration, but best of all, I now take true pride in myself and all I have to overcome in my role as a family caregiver.

In identifying ourselves as family caregivers we are saying that family caregiving is not just a personal issue for those involved, to be dealt with only within the confines of our family, but rather a national issue that must be addressed. By identifying ourselves as family caregivers, we are calling attention to the inequities in our healthcare system. By identifying ourselves as family caregivers, we are saying we matter. By identifying ourselves as family caregivers, we are alerting researchers, policy makers, payors and others in a position to make a difference, to the impact of family

Suzanne Mintz

caregiving on us as individuals, on our families, and on society at large.

Being a family caregiver is not the end- all and be-all of my identity, but it is definitely part of it. It cannot, and should not, be denied.

Nurturing your inner self

There is another identity that I believe we need to claim as well, with just as much fervor, but hopefully with more delight. It is our individual identity, the core of our personality, the things that make us happy, that let us say: "I feel like 'me' when I am doing this or that, or I like 'me' when I am being this way."

One of the greeting cards that the National Family Caregivers Association (NFCA) sent to its members some months back depicted a cartoon character trying to maintain many, many hats on his head, and having a great deal of difficulty doing it. The message read: "You wear so many hats it's easy to forget who you are sometimes." Inside it said: "So remember to take off those hats now and then and get back in touch with the inner you."

How do you do that when you are a caregiver; how do you reassert, or find the inner you, when you rarely—if ever—have personal time? The easiest answer is you make the time, you prioritize 'you' but that begs the question. The reality is so very much harder.

But caregiving so often keeps us off balance. It is so easy to get lost in its physical and psychological maelstrom—the sadness, the frustration, the stress and strain on your body and your mind, the financial worries, the emotional pain. All the more reason to step out of the frame on a regular basis and rekindle your special light by cultivating the other parts of yourself, to learn to give to yourself in addition to giving to others.

Rabbi Hillel said many years ago, "If I am not for myself, who will be for me? If I am only for myself, what am I? And if not now, when?" He was a wise man, and he recognized the need for all of us to have balance in our lives and serve ourselves as well as others. His message is a wake-up call to all caregivers that loving yourself is not selfish. It is in fact a way of honoring and valuing the wonder of a human life.

The inner person in each of us is different, and we all need to find our own way of keeping in touch with ourselves and developing that awareness of what fulfills us. When we find that, we can make it an identifiable piece of our lives that we can turn to for energy, solace, and validation. It might be the time you spend in church that allows you to separate yourself from caregiving for a time and that brings you peace or the morning jog you take that provides a surge of energy and a sense of well-being. It might be the career that not only "brings home the bacon," but also provides you with personal satisfaction. It might be as simple as a 15-minute bubble bath you allow yourself every Friday evening as a way to calm yourself down and welcome the weekend.

It is not an easy thing to do, especially when you're racing around and perhaps living from crisis to crisis. It is not easy because doing so often makes us feel guilty that we are taking time away from fulfilling obligations, or if you're like me, you've felt guilty just because you are healthy and your loved one is not. Having suffered through two bouts of clinical depression, during which I considered death a welcome relief from life, I learned the value of having a piece of my life that is apart from caregiving, of creating some balance between caring for others and caring for myself, of loving the fact that I am healthy. Now that both my professional life and my personal life have a caregiving focus, I know that finding and nurturing a fragment of my soul that gives me pleasure and a separate identity is more important than ever before.

But how do you do it? There's that pesky question again. You do it, I believe, by first believing in your value as a human being and your right to a few minutes of personal space at least several times a week. If you can take more than that, it is a bonus from which you will prosper. But all of us, even the busiest of caregivers, can find 10 or 15 minutes several times a week to care for ourselves. The trick is to start and to focus those few minutes on you, your interests, your dreams.

I spoke to my mom this morning, herself a caregiver for my dad who had a stroke two years ago and now suffers from mild dementia and bouts of incontinence. She said she had a free flight from one of the airlines but wasn't sure that she could use it because of all the adjustments, both physical and emotional, she would have to make so that my dad was cared for in her absence. "Do it mom!" I said, "Do it for yourself—so that you can hear your laughter. Come visit me and we'll take walks together and reconnect. Love, honor, and value the essential part of yourself that you've slowly been losing to caregiving. Do it because if you are not for yourself, who will be? And if not now, when?" ■

This article is adapted from two which originally appeared in two parts in Paraplegic News. Copyright Suzanne Mintz

Suzanne Mintz is President and Co-Founder of the National Family Caregivers Association, a charitable, membership-based organization dedicated to making life better for all of America's family caregivers. For information call: (800) 896 3650, or write: NFCA 9621 E. Bexhill Dr., Kensington, MD 20985-3104; Web site: http://www.nfcacares.org; E-mail: info@nfcacares.org.

Pausing to Reflect on The ADA After 10 Years

by Dick Thornburgh and David R. Fine

Peter Thornburgh suffered a brain injury in 1960, when he was just 4 months old. At that time, our country was not very hospitable to people with disabilities. By the time 2-year-old Kenneth Fine was diagnosed with autism in 1996, much had changed.

In the 1960s, there was little in the law to help people with disabilities meet their full potential and participate as active members of our society. The 1970s brought the Rehabilitation Act, the Education for All Handicapped Children Act (now known as the Individuals with Disabilities Education Act—IDEA) and the Developmentally Disabled Assistance and Bill of Rights Act. Those laws were limited, both by the topics they addressed and the people or entities they regulated.

DICK THORNBURGH

Societal views were not much better. During the decade in which considerable attention was focused on civil rights for so many Americans, Peter's mother had to confront a school principal who justified placing students with mental retardation in a dank cellar because "they don't care." The 1970s and 1980s did not see much improvement. People who used wheelchairs were denied access to far too many places by easily correctable barriers such as high curbs and too-narrow doors. People who were hard of hearing or deaf were excluded from the most basic of public services, including the 911 emergency telephone service so helpful to others. Despite the ease of adding Braille instructions, people with visual impairments all too often confronted bank machines and elevator controls that were unusable to them. Hundreds of similar examples describe a society that, if not hostile to the needs of people with disabilities, was certainly ignorant and apathetic to those needs.

It was against this backdrop that on July 26, 1990, President George Bush gathered 3,000 Americans on the lawn of the White House to watch him sign into law the Americans with Disabilities Act (ADA) and to hear him proclaim: "Let the shameful walls of exclusion come tumbling down." Within a year of that sun-drenched signing ceremony, the Justice Department wrote and published extensive regulations to flesh out the requirements of the law.

High hopes for ADA

The ADA was and is the most comprehensive legislation ever to address the rights and needs of those who face the challenges of disability. It prohibited discrimination based on disability in employment; in government programs and services; in public transportation; in communication and in places of public accommodation such as department stores, amusement parks, theaters and airliners. The ADA aimed high: not only to prohibit discrimination but to require employers, government offices, public transit, and businesses open to the public to take reasonable, and usually minimal, steps to accommodate the needs of people with disabilities. On the day the ADA was enacted, Iowa Senator Tom Harkin called the new law the "20th Century Emancipation Proclamation," and Utah Senator Orrin Hatch predicted that "America will be a better place because of the action we have taken."

Was Senator Hatch correct? Undeniably. Has the ADA so far lived up to the ambitious hopes of its drafters and supporters? The answer is, as Supreme Court Justice Ruth Bader Ginsburg wrote in a recent opinion interpreting part of that law, "a qualified yes."

Success stories

There are innumerable examples of the ADA's success:

ACCESS

- A person who uses a wheelchair can now participate fully in the deliberations of the city council in Waukesha, Wisconsin, after the city agreed to hold all of the council's deliberations in an accessible room.
- A great many more fans of country singer Hank Williams, Sr., will be able to visit his childhood home in Georgianna, Alabama, after that city agreed to remove architectural barriers that prevented wheelchair access.
- As a result of the settlement of an ADA complaint, the Houston, Texas police will provide their officers with training to more effectively communicate with witnesses, victims, and suspected criminals

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who have hearing difficulties.

- People who use wheelchairs will have an easier time enjoying New York City, where the owners of the Empire State Building have agreed to modify that building's lobby, restrooms and observation decks to remove barriers; and the New York Yankees have promised to add hundreds of wheelchair-seating locations to "The House that Ruth Built."
- Financial giant Wells Fargo is in the process of adding talking ATMs at 20 sites in California so that those with vision problems can enjoy the convenience of those machines.

EMPLOYMENT

There can be no question that the ADA has increased opportunities for people with disabilities to enter this nation's workforce. One study showed that the number of people with severe disabilities employed in the United States rose three percent in the first five years after the ADA became law.

COMMUNITY INTEGRATION

There has been good news for those who receive care in state-run institutions or community integrated group homes. In its 1999 decision in *Olmstead v. L.C.*, the Supreme Court held that the ADA requires that states provide services to people with mental or developmental disabilities in the most integrated setting deemed appropriate by medical professionals.

Thus, many of those walls that President Bush spoke about when he signed the ADA into law have come down, and others will soon follow.

Some bad news with the good

While the ADA's supporters can and should revel in these successes, an evaluation of the Act after its first decade must fairly include some disappointing news.

Though the number of people with disabilities who are employed has increased, it remains the case that about three of four people with severe disabilities do not have jobs.

There are a great many possible reasons for that unfortunate statistic:

- It may be that some of those who are not employed contend with disabilities that prevent their joining the workforce.
- It may be that there has been a delay in the entry of people with disabilities into the workforce because those people have only just recently been afforded the opportunities for education and training necessary for jobs in our increasingly technical society. There is statistical support for this theory. The National Institute on Disability and Rehabilitation Research reports that just 29 percent of young people with disabilities attended college in 1986, but that the number had risen to 44 percent just four years after the ADA became law. Those students have only recently entered the job market, and we have good reason to hope that the employment statistics for those with disabilities will continue to improve.

DAVID R. FINE

> There can be no question that the ADA has increased opportunities for people with disabilities to enter this nation's workforce. One study showed that the number of people with severe disabilities employed in the United States rose three percent in the first five years after the ADA became law.

- Sadly, another reason may be that some employers remain resistant to employing those with disabilities because they believe that a worker with a disability is more likely to miss work or that the accommodation needed to assist such a worker would be costly. They are, in most cases, mistaken. A major employer recently reported on the results of a 30-year study of its workforce that showed that employees with disabilities met or exceeded the average for job performance and easily exceeded the average for safety and attendance. Moreover, another study demonstrated that, on average, accommodations for workers with disabilities cost employers less than $100 for each such worker.

While there have been victories in the courts, there have also been judicial decisions that have narrowed the reach of the ADA, and there is a likelihood that more are yet to come. Cases interpreting the coverage and requirements of the ADA have only just recently made their way to the Supreme Court and the statute has had a mixed reception there. For example, the courts have grappled with the question of what conditions are "disabilities" that are covered by the ADA. Last year, the Supreme Court examined the definition of "disability" and concluded that conditions that can be corrected—such as near-sightedness that can be remedied with glasses or contact lenses—are not disabilities for purposes of the ADA. Even in its decision in *Olmstead*, which considered whether people with mental or developmental disabilities are entitled to the most-integrated living arrangements appropriate for their needs, the Supreme Court answered only with a "qualified yes." In her opinion for the Court, Justice Ruth Bader Ginsburg wrote that states might be excused if their financial resources prevented them from providing community placements.

The ADA faces another legal test this coming year. The Supreme Court will consider a case that asks whether the states are shielded by the Constitution's Eleventh Amendment from private suits in federal court to enforce the ADA. If the Court sides with the states in *University of Alabama Board of Trustees v. Garrett*, as it may well

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Your child's disability may have been preventable

Your child may have been harmed by something that happened during pregnancy, labor, or delivery, or by exposure to a toxic substance. Parents often have no way to know what might have caused their child's disability.

Let us review whatever information you have about your child's disability. If it turns out that the disability was preventable, your child may be entitled to receive compensation to pay for the best care available, as well as for all the other losses.

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do, the result would be to eliminate one means of enforcing the requirements of the ADA. Private citizens could no longer bring lawsuits in federal courts seeking to enforce the ADA directly against the states. Many in the disability-rights community justifiably worry about the effect on ADA enforcement if the Court reaches such a conclusion. It is important, though, to understand that a decision in favor of the states in Garrett would not prevent the federal government from enforcing the ADA against the states, and it would not affect the ability of private citizens to enforce the ADA against most local governments and private businesses.

How well has the federal government met its responsibility to enforce the ADA?

The National Council on Disability, an independent federal agency, reported this past June that most federal agencies charged with ADA enforcement are under-funded and under-staffed. As a result, the NCD concluded, despite the best of intentions, federal enforcement of the ADA in its first decade has been "weak."

Although many businesses have accepted and even embraced ADA guidelines, serious challenges remain. A number of business owners—among them actor Clint Eastwood—have charged that unscrupulous lawyers have taken advantage of the law's provision allowing successful plaintiffs to recover their legal fees from defendants. In congressional testimony this year, Mr. Eastwood, who owns a hotel in Carmel, California, alleged that lawyers look for minor ADA violations, bring suits, and collect huge fees. He told a legislative committee that the law should be changed to give businesses 90 days' notice before a lawsuit can be filed to correct any problems. Many ADA supporters respond that people with disabilities have waited long enough for businesses to comply with the law. There is, of course, merit to both sides of this argument.

Perhaps most telling—and most disturbing—is a 1998 survey sponsored by the National Organization on Disability and Louis Harris & Associates. Pollsters questioned 1,000 people with disabilities and found that the majority of them believed that the ADA had not had a substantial effect on their lives.

A good beginning

And, so, this tenth anniversary of the ADA brings with it a decidedly mixed report. Many of the hopes and aspirations of those who gathered on the White House lawn a decade ago have been met, but many others have not. The ADA's sponsors and supporters understood—and still understand—that the law is not the goal in itself but a means to reach the goal. The struggle is to win the hearts and minds of Americans and to give people with disabilities the opportunity to dispel the old myths about what they can and cannot do. That is no small task, and it will take years of effort and education.

For Peter Thornburgh, Kenneth Fine, and millions of other Americans with disabilities, as well as their families, friends and supporters, this tenth anniversary provides an opportunity to take stock of the effect the ADA has had. We should draw from that assessment not a sense of disappointment that the ADA has not yet achieved all that we hoped it would and that, in some quarters, the law is under challenge, but a renewed commitment to its lofty goals. As Shakespeare wrote, "What's past is prologue." ■

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Dick Thornburgh (father of Peter) is counsel to the law firm of Kirkpatrick & Lockhart LLP. He served as Governor of Pennsylvania between 1979 and 1987 and as Attorney General of the United States between 1988 and 1991. During his tenure as Attorney General, he spearheaded Bush Administration support of the ADA and oversaw drafting of the Department of Justice regulations implementing the Act. David R. Fine (father of Kenneth) is also a lawyer with Kirkpatrick & Lockhart LLP. Messrs. Thornburgh and Fine filed an amicus curiae brief with the Supreme Court in the Olmstead case on behalf of the National Organization on Disability.

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Circle #16

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Talk About a Good Time!

Celebrate...Communicate Day gets kids with communication devices talking and smiling

by Debra Brubaker

Fun, games, friendships, and a little learning are all part of the mix of magic and delight—the main attraction—of the annual Celebrate...Communicate Day (CC Day). Since 1997, children who have speech impairments from 17 school districts in central Pennsylvania have gathered to delight in a day created especially for them. At CC Day, magical things are happening with kids using technology!

Our celebration gives students who use augmentative or alternative communication the opportunity to meet others using similar systems. These children seldom get the chance to socialize with their peers, as each is usually the only student in his or her classroom (sometimes even the school district) who uses a communication device. CC Day is filled with learning games, entertainment, and networking between parents. Most important, however, it provides children who use the communication devices with the chance to share and talk with their peers in an environment where they feel comfortable.

ABOVE: "Callin' All Cowpokes!" was the theme for the May 2000 Celebrate...Communicate Day (CC Day). Here all the participants come together in a big roundup.

LEFT: Bill Herrity of Bloomsburg, PA, uses his communication device to let everybody know he is having a good time at last year's CC Day. The annual event gives students like Bill the opportunity to meet and have fun together.

Visualize a big-top circus tent filled with 80 young people, ranging in age from 3 to 21, and lots of parents, teachers, therapists, and volunteers. Imagine eyes lighting up and smiles growing as these children renew old friendships and make new ones. Together they delight in the entertainment, interact with each other, and play learning games that have been adapted to their special needs.

How it all began

My daughter, Ashley, 13, has cerebral palsy, developmental delay, and speech impairment. We are very fortunate to live in an area of Pennsylvania where we have access to the Central Susquehanna Intermediate Unit (CSIU)—a regional education service agency that provides instructional support.

Through the dedicated work of the CSIU team, Ashley was given the opportunity to find the communication device that best fit her needs. At times, it was a frustrating road to travel, but we finally found the right device. At the time, Ashley was 5 years old and attending kindergarten and a language development class. She was the only child with such a device.

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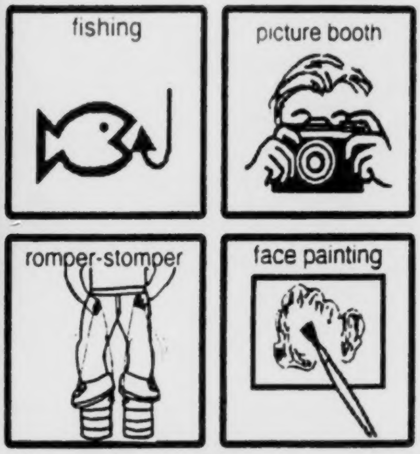

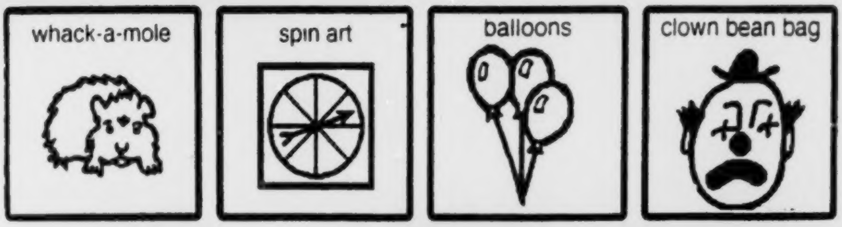

TOP: Volunteer Jonas Pfleegor awards Ashley Brubaker with her prize (a book) for winning one of the learning games.

MIDDLE: Some of the vocabulary illustrated the games that were available so the students could communicate their choices.

BOTTOM: Keil Russell of Mifflinburg, PA, tries creating some art at the spin art booth.

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It was complicated and we had no idea what to expect from it. Her teachers and aide were concerned about how this device could be incorporated into Ashley's school day. There were many questions to be answered. Though we attended seminars, which taught us how to use the device, we still had few ideas on how it would fit with Ashley's day-to-day activities.

Then we had an eye-opening experience. Ashley was invited to participate in Augmentative Communication Electronic Systems Day (ACES), a workshop for children with speech impairments. The workshop was held for children who used augmentative communication devices so they could interact with and meet other children using similar devices. The location of the workshop was three hours away by car, but we went anyway. We just had to find out what it was all about.

Entering that room filled with children just like Ashley, we knew we were witnessing something magical. Children with speech impairments were communicating with other children with speech impairments. Their bright eyes and smiling faces lit up the room. The sound of computerized voices was music to our ears.

We left ACES Day with mixed feelings. We were excited that Ashley finally got an opportunity to participate in an environment where she was just like everyone else. We were, however, disappointed that other children with speech impairments could not experience the same feeling of acceptance. We were challenged because we knew that we had to capture the magic of ACES Day and bring it home to the special children of CSIU.

Organizing a workshop like ACES Day for the children in central Pennsylvania was not going to be easy. It would take the hard work and dedication of parents, teachers, and CSIU staff. The idea was presented to Dr. Robert Witten, executive director of CSIU, and Ms. Judy Jenkins, the CSIU director of special education. They agreed that this was a great idea and decided to appoint a committee consisting of members of the CSIU staff and parents of children with special needs. We scheduled the first CC Day

Bringing these students and their parents together on a regular basis, in an environment that enables them to communicate, is rewarding for everyone.

for May 6, 1997, and convened the first planning committee in August 1996. There would be much to do, but the team at CSIU rose to the challenge.

The committee decided to define which students would be invited: we agreed CC Day would be for students currently using some form of alternative or augmentative communication device. This could be anything from a simple cardboard language board to a super high-tech electronic communication device. We also defined the purpose of CC Day. Ours was three-fold: to provide students with the opportunity to meet others like themselves and to use their device in a setting outside school or home; to provide an arena where they could celebrate a successful year of learning; and to provide families of these students with a chance to network.

With our goal clearly set, we thought about how we would accomplish it. We wanted to have games, food, and entertainment. We had to come up with games that could be adapted to the students' abilities. Then we would have to list the vocabulary for the students' communication devices so they could indicate their choices throughout the day—from food to games to personal needs. We would require funding for the undertaking, have to arrange transportation, publicity, and many more details. (See sidebar p.66 for more information.)

With the date set and the committee chairs in place, we still had to come up with a slogan and theme for the first CC Day. As we thought back on how it all started, the only consistent word was, "magical." It seemed fitting that our first CC Day should revolve around magic, so it became the theme and the slogan was "Magical Things Happen When Kids Use Technology." We were not to be disappointed—the first CC Day was a triumph, filled with the sounds of children laughing and clapping as they enjoyed the entertainment, and with a sense of accomplishment as they communicated their wishes.

Looking ahead

After witnessing the great success of our first CC Day, it was clear how vitally impor-

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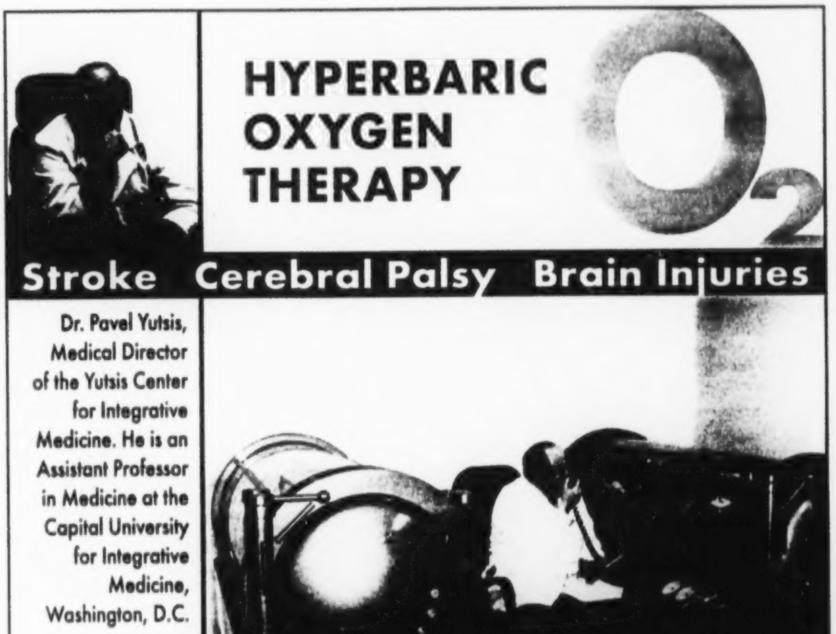

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Circle #68

How to have a Celebrate...Communicate Day

A few of the special kids who gathered for this year's CC Day give a toot on their kazoos. The kazoos were donated as prizes for one of the many learning games at CC Day.

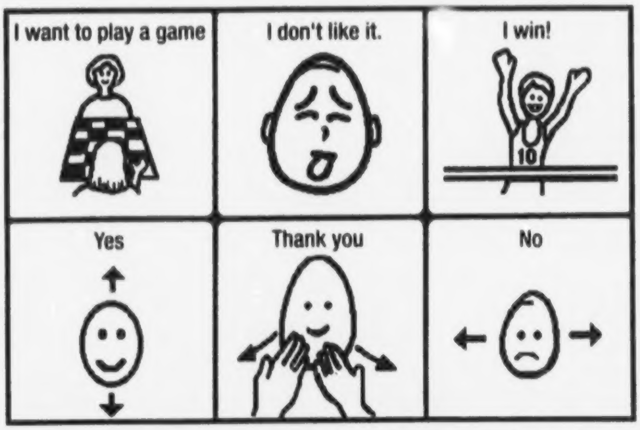
Though CC Day is a magical experience, it was not created by waving a wand. It took the hard work and dedication of many people and quite a bit of planning. With logical organization and a good deal of creativity, our celebrations have been great successes. There are many details to cover, but here is our basic blueprint, which breaks down tasks into manageable areas:

Eight to nine months before the event, an invitation list was compiled from a master list of all the students who use alternative communication in the CSIU region. When we knew how many students would possibly be participating, the committee decided on an appropriate facility for the event. The site had to be able to accommodate all of the students as well as parents and aides, tables, chairs, tents, and bathrooms. In the past, we have held CC Day in the CSIU building parking lot.

Responsibilities: Each member of the planning committee was chair of a particular area (food, fund raising, games, publicity, or transportation). The chairs reported each month to the committee to give a progress report.

Volunteers: A couple of months before the event, the search for volunteers from the school and the community began. These volunteers were responsible for the food stands, games, and other chores associated with the event. The committee instructed the volunteers in their specific responsibilities, and gave a brief overview of augmentative communication devices and some suggestions for relating to the students.

Games: Because the students attending CC Day would have differing abilities, games that could be played by everyone were chosen with the help of occupational therapists from CSIU. Some of the games we chose were golf, ring toss, balance beam, sponge toss, jump in the balls, and other types of activities.



Above: Some of the "vocabulary" for the students' communication devices included words or phrases that they would need to enjoy the games.

Once the list of games is decided on, each member of the planning committee is responsible for purchasing supplies for one or two games. Twelve games are the average for a CC Day event.

Vocabulary: CC Day illustrates the importance of alternative communication as a system—allowing students to communicate with people in all areas of their lives. For the students to be able to participate in the games at CC Day, a vocabulary was established for their AAC devices. Several members of the planning committee, which included CSIU speech therapists, established a vocabulary to be given to parents about a month prior to the event. Enough time had to be allowed so that the students and their support teams could program the vocabulary into their AAC devices. Vocabulary consisted of the words or phrases that the students would need during the day: food choices, game choices, asking for another turn at a game, expressing hunger, thirst, or fatigue. Handouts of the vocabulary were also available during the event and were posted at each station. The vocabulary was adjusted to suit each student's needs.

Fundraising: Funds were needed not only for supplies but also for prizes. A letter was distributed about five months prior to the event describing it, and what made it special for the children involved. This letter was distributed to local companies, as well as to local media and television. Sponsors donated many items as well as financial support. For example, each student attending CC Day was given a backpack and a T-shirt as mementos and prizes during the day. Donations varied in amount, but we were able to attract some major sponsors, who gave at least $200. We reached out to large companies like our area newspaper, national corporations, and restaurants, especially those with local outlets in the community.

Publicity: Public relations and publicity activities were carried out by all of the committee members with input from school personnel, parents, and students, as well as those who supported our fundraising efforts. Specific publicity activities included the development of news releases, which were sent to all local news media. Announcements were also made to members of the CSIU special education program, its board of directors, staff from other departments, school district administrators and the neighborhood around the school office building (who were not accustomed to seeing a circus tent in the parking lot).

Food and prizes were also essential for CC Day. The menu revolved around the theme of the particular event. For example, the 1999 CC Day was "Lets Talk Circus." The menu included foods like hot dogs, pizza, popcorn, cotton candy, and peanuts. This year's CC Day, "Callin' All Cow Pokes!" , had a western theme, and included barbecue, chips, baked beans, and trail mix. The food was donated from local bakeries, supermarkets, beverage distributors, and CSIU employees.

Entertainment: The attractions differ according to the particular theme of the event. In the past, entertainment has included clowns, storytellers, and face painters. This year, we featured hayrides, a dog show, dancers, a fiddler, and lots of balloons! Most of the performers have been eager to volunteer their time.

Transportation: Permission was necessary for transporting the students to the event, so forms were sent out to the parents of the invited students. The transportation schedule was set up by coordinating with the schools in the entire district.

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tant such an event can be. Bringing these students and their parents together on a regular basis, in an environment that enables them to communicate, is rewarding for everyone. We have since celebrated with themes like "We're on the Ball, Talking to All," which had activities revolving around sports, "Let's Talk Circus," and this year's

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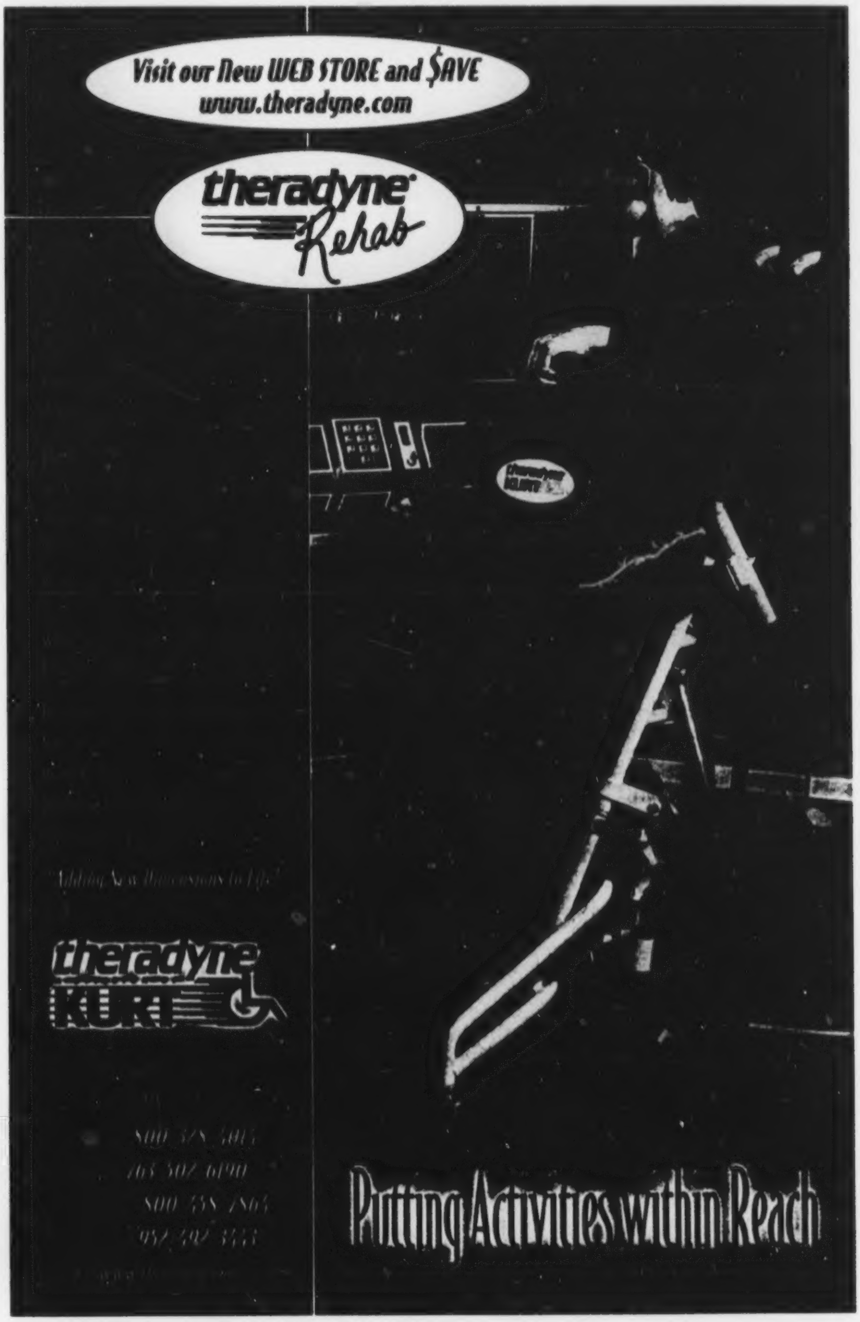
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Circle #62

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902

LEFT TOP: Michael Fasold of Sunbury, PA is intent on one of the games.

LEFT MIDDLE: Jim Hoffman uses a switch to communicate his preference for a ring toss game.

BOTTOM: Nancy Geise of Northumberland, PA, uses a hand-held electronic communication device. She is sporting her backback—one of the mementos donated to CC Day by sponsors.

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western theme, "Callin' All Cow Pokes!"

We are constantly reminded that our special kids cannot magically fit into today's society. They must continually strive to communicate and be a part of their surroundings. Their lives are full of uphill battles. Celebrate... Communicate Day is one way we can work toward triumph in those battles. ■

Debra Brubaker, her husband Myron, and their children, Ashley and Craig, make their home in Selinsgrove, PA. Mrs. Brubaker can be reached for more information regarding CC Day by mail at RD#2, Box 225 N, Selinsgrove, PA 17870, e-mail: humming@ptd.net; Web site: http://www.csiu-ccday.org

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Circle #24

New Web site launched to help parents access resources for children with disabilities

The U.S. Department of Education has created a new Web site to help America's infants and pre-schoolers with disabilities and their families. The site focuses on the efforts of the Federal Interagency Coordinating Council (FICC). The council facilitates federal, state, and local activities related to serving infants, toddlers, and pre-schoolers who receive services under the Individuals with Disabilities Education Act (IDEA), as well as other federally funded programs such as healthcare, child care, and social services. The site, http://www.fed-icc.org, will provide a useful storehouse of information for parents of children with disabilities, as well as state and government agencies. For parents, the Web site is user-friendly and easily navigable, offering access to names and numbers of people throughout the government who can help answer questions about children and disability issues.

Eplibrary.com now offers online shopping

WWW.EPLIBRARY.COM

Exceptional Parent Library, a division of Exceptional Parent magazine, one of the largest sources of books, videos, CD's, and software for the disability community, has announced the addition of online shopping on their Web site. This new feature makes it even easier for parents, educators, and professionals from around the world to obtain any of the products in the Library simply by clicking a button. Eplibrary.com currently lists and details books, videos, CD's, and software in almost 50 need-specific, as well as general categories. Along with the addition of the online shopping features, the Library provides reviews on many of the titles, providing even more in-depth information.

CALENDAR OF EVENTS

9/13-16 Alliance for Children and Families Annual Conference

Sheraton Cleveland City Centre, Cleveland, OH

Workshops will include early childhood development, managed care, and treatment of childhood trauma. For more information contact the Alliance for Children and Families at (800) 221-3726 x 3688; E-mail: kjackson@alliance1.org; Web site: http://www.alliance1.org.

9/14-17 International Conference of Turner Syndrome Societies

Hyatt Regency Woodfield, Schaumburg,IL

A wide range of topics concerning Turner Syndrome will be covered, including new genetic research, growth hormones, and invitro fertilization. For more information contact the Turner Syndrome Society at (800) 365-9944; Web site: http://www.turner-syndrome-us.org.

9/21-23 American Academy for Cerebral Palsy and Developmental Medicine (AACPDM)

Sheraton Centre, Toronto, ON, Canada

This conference is mainly for professionals who care for individuals who have cerebral palsy. Attendees can choose from 32 instructional courses, 7 free papers, as well as several "Breakfast with the Experts." For more information contact AACPMD at (847) 698-1635; Fax: (847) 823-0536; E-mail: king@aaos.org; or Web site: http:// www.aacpdm.org.

9/22-24 Abilities Expo

Capital Expo Center, Chantilly, VA

This conference will show the latest in assistive living products and services as well as seminars on insurance coverage, government regulations, and available services. For information call (800) 382-3085; Web site: http://www.abilitiesexpo.com.

9/27-30 Sickle Cell Disease Association of America, Inc. 28th Annual Conference "A Focused Future: Care & Cure in the 21st Century"

Greensboro Sheraton at Four Seasons, Greensboro, NC

The convention will include lectures, interactive workshops, keynote presentations, technology, networking, and exhibits. For more information call (800) 421-8453.

VISIT OUR WEB SITE, WWW.EPARENT.COM, FOR UP-TO-DATE INFORMATION ON THE WORLD CONGRESS AND EXPOSITION ON DISABILITIES.

FamilyEducation Network announces partnerships

FamilyEducation Network, the Internet's largest K-12 and parent network, has partnered with The Council for Exceptional Children (CEC) and The National Association for Music Education (MENC). The two organizations will provide educational content and advice for parents and educators throughout FamilyEducation Network's network of Web sites.

FamilyEducation Network will be CEC and MENC's primary Internet partner, promoting school-home communications and family involvement via the Web. This partnership will provide CEC and MENC with a key communication channel to parents and educators on a national, state and local level.

Resources and expert advice from CEC and MENC are already featured on familyeducation.com and teachervision.com. These partners will also be contributing to the development of educational games on funbrain.com, the largest source for free online quiz-building and assessment tools.

FamilyEducation Network will also provide free online services and training to CEC and MENC members. All members will be able to develop their own free Web site on myschoolonline.com using its free web-hosting and web-building tools. FamilyEducation Network contains Web sites that include familyeducation.com, teachervision.com, funbrain.com, schoolcash.com, myschoolonline.com, and infoplease.com.

PACER fact sheets on health available

PACER's Health Information and Advocacy Center has developed a series of fact sheets on managed care and rights in the healthcare system for families of children with disabilities. Single copies are free to families. The following fact sheets are available:

"Access to Your Child's Health Records," "Coverage of Dependents," "Home Care Bill of Rights," "Minnesota Patient's Bill of Rights," "Release of Your Child's Health Records," "Is Your Plan Self-Insured?" and "Strategies for Appealing Health Plan Decisions." To obtain the fact sheets, call PACER at (612) 827-2966 or go to their Web site at http://www.pacer.org/health/.

American Diabetes Association.

American Diabetes Association launches new youth program

The American Diabetes Association has launched a new program targeting young people who have the disease. This new project is a four-part program that includes "Wizdom," a kit for kids and their parents. The kit consists of two notebooks, one created especially for the child and one written for parents. The story line throughout the kit centers around "The Amazing Audrey," a 14-year-old "diabetes wizard." Audrey takes on a new wizard apprentice, AJ, a boy who has just been diagnosed with diabetes. Throughout the course of the books, Audrey teaches AJ how to juggle—that is how to juggle his food, insulin, and exercise in order to achieve and maintain good diabetes control. The kit will also include a tabbed binder to be used by the children and their parents as they build their own diabetes information resource guide. The books and binder will fit into a cardboard box that will house further "goodies" like food samples, recipe cards, stickers, temporary tattoos, pens, and magnets.

The kits will be distributed free of charge through the American Diabetes Association's toll-free number upon referral from physicians or other diabetes care providers. A new "YouthZone" on the Association's Web site—http://www.diabetes.org/wizdom—features the Wizdom characters.

Product Recall Information

In cooperation with the U.S. Consumer Product Safety Commission (CPSC), Vtech Industries, LLC., of Wheeling, IL, is recalling about 34,000 toy baby phones. The toy phones have a ball-shaped antenna which can detach, presenting a choking hazard to young children. The toy is called Little Smart Soft Songs Baby Phone. For more information contact VTech at (800) 521-2010 for a replacement phone or visit their Web site at http://www.vtechkids.com/html2/recall.html.

The U.S. Consumer Product Safety Commission protects the public from unreasonable risk of injury or death from 15,000 types of consumer products under the the agency's jurisdiction. To report a dangerous product or product-related injury, and for information on CPSC's fax-on-demand service, call their hotline at (800) 638-2772 or CPSC's teletypewriter at (800) 638-8270. Consumers can obtain this release and recall information at CPSC's Web site: http://www.cpsc.gov. Consumers can report product hazards via e-mail at info@cpsc. gov.

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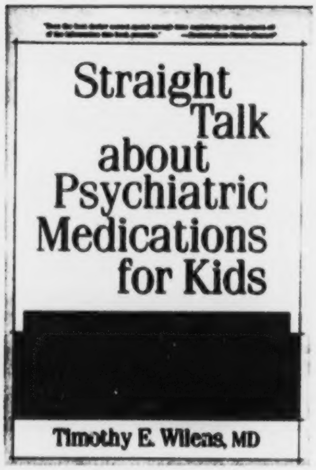


STRAIGHT TALK ABOUT PSYCHIATRIC MEDICATIONS FOR KIDS

Timothy E. Wilens, MD
1999;The Guilford Press, New York: 279 pages
Available through the EP library: (800) 535-1910; code: GL11GN
Cost: $15.95
plus shipping and handling

Straight Talk About Psychiatric Medications for Kids is written in parent-friendly language and answers questions about psychiatric medications. The book is divided into three parts. "What Every Parent Should Know About Psychiatric Medications for Children" is first. It addresses potential parental concerns, ranging from preliminary evaluation and diagnosis to therapy and medication. Presented in a question-and-answer format, parents can read selectively, choosing the questions that apply to their child. It also includes definitions of medical terms that may be encountered.

In Part II, "Common Childhood Psychiatric Disorders," there is an informative section that describes the symptoms, causes, and development of disorders over time. Each chapter in this section concludes with an examination of the major interventions, both medical and psychological, used in treating the particular disorder discussed. Disorders are grouped by related symptoms, so they are easy to locate.

The third and last part, "Psychotropic Medications," offers detailed descriptions of the various categories of medication used to treat psychiatric disorders. The side effects and dosing information are explained and discussed. Again, a question and answer section is featured.

Following is an excerpt from the second chapter of Part I: The Psychopharmacological Evaluation: Finding Out What's Wrong:

> *"Our daughter has had behavioral and emotional problems over the years, and she has seen her school psychologist regularly. Now, though, the school is recommending a professional evaluation, and I have no idea what it involves. What is it likely to include?*

"As in any field of medicine, the first step in treating a disorder or disease is to figure out what is wrong. Your daughter's school is urging you to do just that, and until you're confident that you have a reasonable idea of the nature of the problem, you should not proceed with medications or any other treatment.

"The diagnostic process, or workup, differs greatly from clinic to clinic but should feel more like an ongoing process because information turned up in one step will determine the next step....Because all children are embedded in their environment, the diagnostic workup must look at the impact the environment has on the child, how the child's problem is interfering with the environment (as in disrupting the family's home life), and how the child's problem and environment are interacting (as in school performance)....

"The basic exam generally will be a one to two hour meeting with a medical practitioner who has mental health expertise or experience....This exam should include a discussion with you, the parents, as well as an interview with and/or observation of your child, often in your presence.

"Your child won't necessarily participate in all of these during the initial workup. Depending on the child's situation, in fact, you may tap these resources as needed over months or even years....As to your situation, your daughter's school may very well have referred you to one or more professionals who can evaluate her. Be sure to ask the practitioner you call what you should expect from the evaluation." ■

Excerpted with permission from the publisher.

Table 2: Elements of the Psychopharmacology Evaluation Process*

Test	Reason
Family evaluation (with a social worker)	To determine what family dynamics, if any, may be contributing to the child's problem; suggest having a family behavioral modification therapist involved in case.
Psychosocial and school assessment (teacher or guidance counselor contact)	To assess child's peer functioning; determine academic and behavioral performance at school.
Psychological testing (with a psychologist)	A broad group of tests that assess the child's emotional and cognitive (thinking) functioning; suggested if there are learning problems not attributable to psychiatric disorder.
Neuropsychological testing (with a psychologist)	Extensive and specific tests to evaluate a child's thinking or information processing abilities.
Structured interviews (varied)	Detailed questions about your child's history; available only at certain clinics.
Medical assessment (with a doctor)	Physical examination and laboratory studies; suggested prior to using medications and when there are concerns of a medical contribution to the disorder.
Medical evaluation (medical personnel)	Thorough history of the child and his or her current and past emotional and behavioral problems; review of above.

*This table represents potential assessments for children with behavioral and emotional disorders. The evaluation process varies greatly dependent on the region of the country, the type of practice, and the circumstances of the child.

PART 1 OF EP'S INTERVIEW WITH JANE BROWNING

A Passion for Advocacy

Jane Browning is executive director of The President's Committee on Mental Retardation. Her life experiences have made her an outstanding advocate for all individuals with disabilities. Recently, she reflected on what has influenced the parents movement for the past thirty years. Following is the first part of our interview.

Living a legacy

The desire to help others was in Jane's family for generations.

"My great-grandmother was a social worker in rural Nebraska. At that time, there were Russian immigrants who had moved into the western part of the state, and they were living in dirt caves. She started taking food to these families and going around the neighborhood collecting clothing. Pretty soon, she had so many goods she went to the county government and said, 'You have to give me space in the courthouse to store all of this stuff.' That became the first social work program in Western Nebraska. She spent the rest of her life working with girls who had severe behavior problems. I still have her case notes about these girls. My sister has been a social worker for 23 years, and my brother was a journalist who worked as a consumer investigator. It's in my blood to be an advocate.

"When I was 23 years old, I was introduced to people who lived next door to people who were running the Citizen Advocacy program at the Denver Arc. The Citizen Advocacy program was started in Lincoln, Nebraska, in 1969. Bill West was the executive director and he was hired to be the director at the Denver Arc. He brought with him a woman named Betty Ferris, who had been running a group home for children in Lincoln. She was the Citizen Advocacy coordinator.

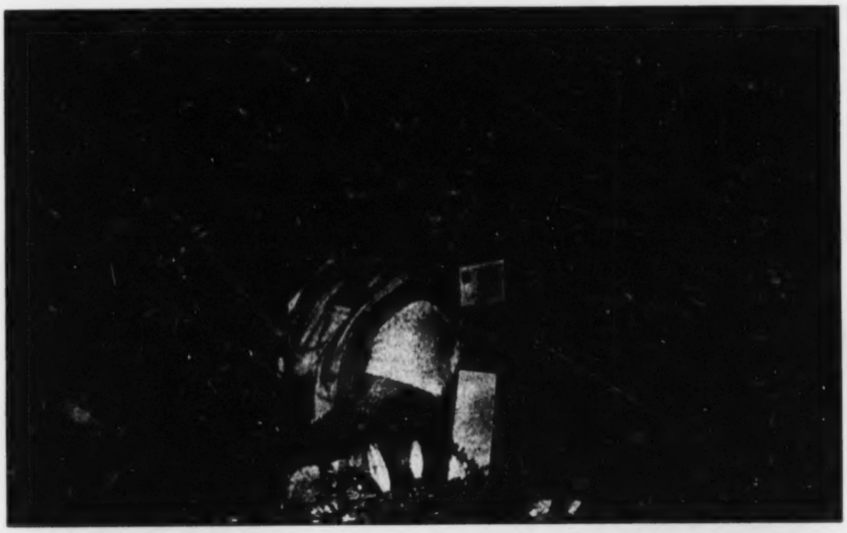
They invited me to join them doing volunteer work on what was to become the first women's group home in Denver. Eight women were moving in, four from an institution and four who had been living with their families. Adult women who were in their 30s, even 40s, were coming out of their homes to a place of their own to live for the first time. This was in 1971."

A woman with a mission

Jane threw herself into the work she was doing with Citizen Advocacy. She met others who were involved with the Arc of Denver, and in her own words, "fell in love with these people."

"I really felt that I had caught on to a mission and the Denver Arc, Bill West and Betty Ferris were at the cutting edge. They had been doing these experimental programs with group homes and the Citizen Advocacy in Nebraska under the influence of Wolf Wolfensburger at the University of Nebraska Medical school. I looked at him as my mentor. He had it right when he formulated the principle of normalization. (The principle of normalization states that it is only in "normal" communities that people with mental retardation will learn behaviors that will lead to social acceptance and allow them greater participation in their communities.) That was in the late 1960s and this is what we are doing now, in the year 2000! Full inclusion in communities is just a natural extension. I've been living this philosophy within the movement all these years. I feel the whole field has finally caught up with Wolf, at long last.

"People always come back to this. It's basic—that what a person with mental retardation needs most is a friend. One friend in the life of any young person is important. But one friend in the life of a per-



At the National Collaborative Academy, September 1999. Jane Browning (right), executive director of the President's Committee on Mental Retardation, poses with her Special Assistant, Lauerdia Roach (left) and Committee member (and past EP Role Model [EP 10/99]) Ann Forts.

son with mental retardation can make all the difference. Moms know that they are usually that person for their child. My goal for my child, the moment he was born, was that he would have someone who would love him in the same way that I do. Someone who would look out for his interests. We are always coming back to the Citizen Advocacy concept. It is such a logical idea."

On the road

Jane wore many hats in her early days with Citizen Advocacy. She was coordinator and executive secretary. She ran the youth group and recruited volunteers for fundraising drives. In addition, Jane wrote the newsletter. Then, she got down to work.

"The National Arc was awarded a Health, Education, and Welfare grant, one of 17 nationally, that were given to national organizations to promote child advocacy, and which demonstrate and research different advocacy approaches. Citizen Advocacy was the model the Arc chose. And for eight years they ran this national program on Citizen Advocacy. I went to the Arc to help coordinate this national approach.

"I moved to Grand Prairie, Texas. I was traveling 70 percent of the time, to 22 states promoting Citizen Advocacy, helping local chapters develop programs, working with model programs in Baltimore, Seattle, Milwaukee, and West Texas, visiting every kind of program under the sun. Everywhere I went I was in the family of the Arc, which was so sustaining to its members. They were a tribe."

Many other brilliant minds were at work, and Jane had the opportunity to collaborate with them. She saw the structure of programs like the Developmental Disability Act taking shape. People had a vision of what was necessary, and, she says, "now it's there and everybody takes it for granted." There was no National Institute on Child Health and Human Development. Jane helped start up these and other organizations.

A family matter

While she was on a plane to visit a model program in Abilene, Texas, she met John Browning, who would become her husband.

"We got married and moved to Little Rock. I worked for the Arc in Arkansas for nine months. I was helping them with a prevention project and then I went to work as the assistant director and then the director of the Arkansas Endowment for the Humanities. I always maintained activity with the Arc as a volunteer. I was the president of the local Arc chapter in Little Rock when I gave birth to my son, Paul Cornelius, now 17, who has Down Syndrome. He is a Junior at Severena Park High School in Maryland.

"I had just been lobbying the legislature in Arkansas to fund a Parent to Parent program. That was in January and in April, I had my son. One of the first things the pediatrician who was on duty said was, 'There's a new program in the Arc—It's called Parent to Parent.' I said,' I know all about it, I wrote the grant! It must be working!'"

Jane then went on to become the state president of the Arc and was appointed by the governor to be on the executive committee of the Developmental Disabilities Council in Arkansas. ■

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Circle #27

A Closer Look at ADD/ADHD

By Vidya Bhushan Gupta, MD, MPH

Attention deficit disorder (ADD) and attention deficit-hyperactivity disorder (ADHD) may affect between four and twelve percent of school-age children in America. I use the word "may" because, over the past decade, physicians, other healthcare practitioners, psychologists and other behavioral therapists, educators, parents, and a broad range of other commentators have argued about the extent of ADD/ADHD in the US population, as well as its causes, symptoms, diagnosis, and treatments. Meanwhile, children and adults with ADD/ADHD continue to try to cope with a disability that interferes with fundamental skills such as the ability to focus and regulate impulsivity which ultimately can encumber academic achievement, hamper friendships and family harmony, impede job advancement, and frustrate social and economic life.

Following is an overview of the disorder—who gets it and why, as well as the signs and symptoms for diagnosis—developed by Vidya Bhushan Gupta, MD, MPH, from his forthcoming book, *No Apologies for Ritalin* (to be published in September 2000). As Director of Developmental-Behavioral Pediatrics at Metropolitan Hospital Center, New York City, Dr. Gupta has extensive experience working with children with ADD/ADHD, their parents, and their families. His book includes a thorough discussion of possible causes and techniques for diagnosis of ADD/ADHD. He attempts to educate parents of children with ADD about various treatments available to treat ADD/ADHD, so that they can make informed choices. It features a lengthy identification and examination of ADD/ADHD treatments—both medications and behavioral therapies—as well as helpful guidelines for parenting a child with ADD/ADHD.

—Maxwell J. Schleifer, PhD

Shawn

Shawn, a 6-year-old African-American child, arrives at the behavioral pediatrics clinic of a city hospital with his 55-year-old foster mother, who is a visibly harried African-American woman. The nurse cheerfully greets Shawn, but, unmindful of her greeting, he walks over to the computer at the nursing station, frantically taps its keys, and returns to pull at the stethoscope hanging around her neck. Not five seconds in the pediatrician's office, he touches the garbage can, the container for discarding used needles, and the blood pressure instrument. He then crawls under the pediatrician's chair to look into the filing cabinet. He continues in this vein despite continued requests to sit down and play with the dollhouse or to draw something. Smiling impishly—completely unaware of the havoc he is wreaking—his large eyes and cute demeanor disguise his turbulent mind.

"He cannot stay still," his foster mother—who is actually his grandmother—says. "He is always on the go, running all over the house, turning on and off the television, opening and closing the refrigerator. He stays up 'til 11 PM and then doesn't fall asleep until midnight. And he even tosses and turns in his sleep. Just look at these notes from school." She pulls a wad of crumpled papers from her pocketbook. His teacher repeatedly reports that Shawn does not sit quietly in the classroom, forgets instructions, disturbs other children, and constantly interrupts her. The principal wants a doctor's note that Shawn is on a medication to calm him before he is allowed back in the classroom.

"Don't touch anything!" his foster mother constantly admonishes the boy, who continues doing exactly what he was doing.

Melissa

Melissa, a 10-year-old Caucasian girl, is brought by her mother to the clinic because she is failing in school.

"Melissa is hyper; she acts silly to get attention, at times even by deliberately offending people. If nothing else works, she touches and pulls at them," her mother says. "She talks constantly, interrupting others, and can't wait her turn."

In school, her mother continues, although Melissa is quick to respond, her answers are often thoughtless and wrong. "She forgets to bring homework home, and, if she does bring it, she either takes three or four hours to complete it or doesn't finish it at all. Her room is always a pigpen. I have to ask her at least ten times before she does anything," her mother continues. "No one likes her. She tries to boss other children around. When they exclude her, she throws a tantrum."

As she enters the room, Melissa rushes to give the doctor, whom she has never seen before, a warm hug. He gently disentangles himself and asks her to draw a picture of her house and the people in it, while he talks with her mother. Melissa turns immediately to the nurse, asks her name, why she is not wearing a white nurse's uniform, and "What's that thing hanging on the wall?" The nurse reminds her of the doctor's request for a picture. Melissa innocently rests her head on her

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closed fist and says, "I forgot." Before the nurse can reply, Melissa interrupts the doctor, "What did you ask me to draw?" Without waiting for a reply or looking at the drawing table, she asks the nurse, "Where are the crayons?" They are on the table. While drawing, she constantly interrupts the doctor with questions, saying "excuse me" each time: "Can I also draw my dog? Can I draw the sun? Is it alright to draw a bird?" She leaves the drawing twice, once to check the door when someone knocks, and once to pick up a ringing phone. She crumples three drawings before she finishes. Her final picture is chaotic, with too many people, things, and animals, each hurriedly drawn and with unnecessary shading. She asks the doctor, "Did I do good?" "Look mommy," she exclaims, "I also drew my cat. Can we go now?"

"Will you shut up!" her exasperated mother shouts.

"How was she as a baby?" the doctor asks.

"A real handful. She was a colicky baby; kept me awake at nights. And a terrible toddler, always running around, always saying 'no!'"

Jason

Jason, a 12-year-old Hispanic child, is brought to the clinic because he is doing so poorly in school that he might be held back. The school wants to evaluate him for special education. His mother says that he is intelligent, but just does not put his mind to his work. "He's a nice kid," she says. "The teacher's too old, she doesn't know how to handle children. She wants to put everyone in special education. He's not hyper, doesn't bother anybody. He's just lazy."

His teacher, on the other hand, reports that Jason is inattentive and daydreams in class. He often looks out the window instead of at the blackboard, and has to be repeatedly reminded to pay attention. He forgets to take notes and does not follow instructions. He fidgets and squirms in his seat, his desk is messy, and his pens and pencils keep falling off. No one wants to sit next to him.

In the doctor's office, Jason sits like an angel, trying to draw a picture of a house, tree, and people in the house. It takes forever. Sometimes he looks out the window, sometimes he twiddles the crayons in his hands, and sometimes he squirms in his chair. When the doctor asks to see what he has drawn, Jason is startled, as if suddenly awakened. His drawing is incomplete.

Are Shawn, Melissa, and Jason normal or abnormal? Healthy or sick?

Making an ADD/ADHD diagnosis

It is difficult to draw a clear-cut line between normal and abnormal child behavior. All children are different and behave along a spectrum that ranges from normal to abnormal. Some children are noisy, some calm; some brash and others polite; some are dynamic, while some are passive; still others are gregarious, some shy. Shawn could be a smart, curious child who wants to touch and feel everything around him. Melissa could be a socially immature girl who will mature with time. Jason's classroom inattention may result from his all-absorbing concern about his parents' impending divorce.

Diagnosis of behavioral disorders does not depend upon telltale signs that can be seen, touched, or heard with the stethoscope.

But the behaviors of all three children are excessive, pervasive, and persistent. Each one displays these behaviors everywhere: at home, in school, in restaurants, in the grocery store, at relatives' homes. They are failing in school and having problems with their teachers and peers. Their symptoms are not in response to a temporary stressor; they have always been like that. Their parents are exhausted and asking for help. These children have crossed the threshold of normalcy.

Could Shawn, Melissa, and Jason just be acting willfully? Children are programmed to please others. They do not act badly intentionally unless they are "driven" to do so by an underlying disease or condition. Children, innately, want to please others; they yearn for approval and accolades. Shawn, Melissa, and Jason are not acting willfully. They behave abnormally because they have an underlying behavioral disorder.

Diagnosis of behavioral disorders does not depend upon telltale signs that can be seen, touched, or heard with the stethoscope. It is inferential—an educated guess at best—based upon a constellation of observed behaviors. Isolated behaviors are not diagnostic; but when a set of behaviors occurs together at a degree and frequency such that the child cannot do what is expected of him (e.g., learn in school) or is not able to relate properly to people around him (parents, teachers, or peers), a behavior disorder is diagnosed.

The children described above are not able to focus and maintain attention, and are easily distracted. All three are impulsive and two are hyperactive. While individually their symptoms are not diagnostic of any disease, together they constitute a disorder called attention deficit disorder (ADD) (also called attention deficit-hyperactive disorder or ADHD). Major symptoms are:

Attention deficit: Attention deficit, or failure to attend to the task at hand, is the cardinal feature of ADD/ADHD. The process of paying attention to a task involves getting tuned into a task and remaining focused on it until the goal is achieved. It is like driving a car: you turn on the ignition (get focused), put the car (body and mind) in proper gear (necessary level of arousal for the task), hold

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the steering wheel in constant check (stay focused), look at the road ahead (stay vigilant), drive at the right speed (tempo), and reach the destination (complete the task) without getting lost due to distractions (off-task activities).

How much attention a child pays to a task depends upon the nature of the task. If it is pleasing, she will pay attention to it effortlessly. Most children are able to focus on a video game or a television show because they get instant pleasure from them, inviting more viewing (a process called reinforcement). Moreover, these programs flood their senses with so much input—flooding the gates, as it were—that other distractions cannot enter their brains. The litmus test of ADD/ADHD is the inability to focus on homework or on a task that does not reward the children immediately.

A child with ADD/ADHD is often the first to raise his hand to give an answer to a question, even if he does not know the correct one.

I have seen two types of inattentive children: those who cannot get focused on any task, the "failure-of-ignition" type, and those who cannot stay focused, the "failure-to-drive" type. "Failure-of-ignition" type children either wander aimlessly doing nothing meaningful or sit passively, looking out the window or twiddling their thumbs. They require constant reminders to begin a task, but may finish what they start. Failure-to-drive type children leap like frogs from task to task, failing to finish anything they start. Despite constant reminders, nothing is accomplished. Children who fail to sustain attention are easily bored and need a constant pep talk to keep up their rapidly fading interest. They burn out quickly. The speed and quality of their performance are very inconsistent: sometimes fast, sometimes slow; sometimes good, sometimes poor. They lack the motivation to accomplish something in the distant future.

Attention in a child matures from the exploratory, rapid, impulsive, and reinforcement-based manner of a 2-year-old (requiring constant approval from the parents) to the slow, deliberate, goal-directed, logical, and productive style of a 12-year-old. The attention skills of children with ADD/ADHD do not mature according to this schedule. Their attention remains divergent and, instead of being driven internally by a goal, is driven by constant reinforcement from the environment (context- and contingency-based).

Distractibility: Children with ADD/ADHD have a tendency to get easily distracted by every little noise or movement in their surroundings. To sustain attention to a task, one has to literally shut the gates of the brain so that irrelevant stimuli do not gate crash into conscious awareness. Children with ADD/ADHD are distracted by every sensation that reaches their five senses. Their situation is similar to a radio that has "constant static" even when it is tuned to a particular station. A truck drives by on the road, and children with ADD/ADHD run to the window, leaving their homework. Someone knocks at the door, and they are the first to ask, "Who's there?" When there are no external distractions, they can have a state of internal distractibility, daydreaming and wandering all over the globe.

The underlying neurological basis of distractibility in children with ADD/ADHD seems to be a lack of sensory filtration at the level of the caudate nucleus, a group of nerve cells in the brain that acts as a relay station for all sensory input before it reaches conscious awareness. Normally, the caudate nucleus serves as a gatekeeper, allowing only relevant stimuli to reach conscious awareness. In children with ADD/ADHD, the head of the right caudate nucleus is small compared with that in normal children and fails to inhibit the onslaught of input from various sense organs on the brain. Every stimulus makes it to conscious awareness.

Impulsivity: Children with ADD/ADHD have a short circuit in their nerve-cell wiring, causing them to act impulsively. They literally respond from the gut, not the mind, and frequently incorrectly. A child with ADD/ ADHD is often the first to raise his hand to give an answer to a question, even if he does not know the correct one. He may actually blurt out the answer without even raising his hand. An adolescent with ADD/ADHD may destroy an appliance because she turns it on without reading the instructions. Adults with ADD/ADHD may impulsively buy stock without knowing the fundamentals of the company, simply because they heard someone in the elevator say it is a good buy. Individuals with ADD/ADHD often get into trouble with the law because they act without thinking about the consequences of their actions.

This tendency to act impulsively rather than reflectively is due to poor working memory, resulting in poor processing of incoming information. The working memory cannot simultaneously hold information about prior experience with an action and its likely consequence. In other words, they have no forethought or afterthought.

A related deficit that results in impulsivity is the inability of children with ADD/ADHD to delay gratification and wait their turn. A child with ADD/ADHD who goes to a restaurant with his parents cannot wait patiently to be served. He calls to the waitress many times despite his parents' admonition, twiddles with the silverware until it falls to the floor, and, finally, gets up and pulls at the waitress's dress and demands his food. This is not a "bad" child. Researchers have shown that impulsivity is not a flaw of character, but a defect of biology.

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Hyperactivity: Although generally considered to be the most salient feature of this disorder because of its obtrusiveness, this symptom is not present in all ADD/ADHD cases. Hyperactivity can be present in various ways: a macro form, in which children are agitated, restless, and move constantly from place to place, touching people and things; a micro form, in which children squirm and fidget in their seats; and a hyperactive tongue (or hyper-tongue) type, in which children are garrulous, talking excessively, often out of context and interrupting others.

Deficits in the brain's executive functions: Executive functions of the brain involve organization, self-monitoring, self-regulation, and continuous quality-improvement functions similar to those that a manager performs in an office. As children grow and develop, they learn to perform these functions. Children with ADD/ADHD do not.

Because of such deficits, children with ADD/ADHD are not able to organize their space and time well. Their desks and rooms are disorganized. They also cannot self-monitor and self-regulate their actions, whether physical or verbal. They thunder around with no concept of the energy spent or the resulting din, even when admonished that they are making the house shake. In a similar way, their volume control can be on permanent "high."

Another result of such executive function deficits is that children with ADD/ADHD are unable to learn from experience. Not only are they unable to monitor themselves, they do not respond to admonitions and advice from those in charge. It is difficult for them to follow rules. This makes them hard to discipline and results in conflicts with those in authority. Parents often complain that their child does not listen, is disobedient, and deliberately tries to hurt their feelings. Sadly, once children organize their self-image around these negative behaviors, they deteriorate into opposition, non-compliance, and defiance.

Children with poor executive functions are also clumsy and accident-prone. They neither plan their movements properly nor execute them smoothly. Unable to track their movements within the environment in which they move, they trip over bumps and fall into holes.

Finally, children with deficits in the brain's executive function process incoming information very superficially. It is with great difficulty that things "sink" into their heads. They often misinterpret what others say, which results in conflicts. They are also unable to process the visual information that they get from others' body language—whether others are welcoming their interruption or are getting annoyed. Not only do they not process external information well, they are also unable to interpret the feedback their brains receive from their own ears, eyes, and body. A child who is shouting at the top of her voice, for example, may not be able to appreciate her mom's reprimand that she was screaming.

Deficits of social behavior: Most children with ADD/ADHD have problems understanding social context and mood (poor social cognition) and are unable to match their behavior to them (poor social adaptability). In other words, they are socially inept: they do not understand whether the social mood is grim or jovial, they speak and act without understanding the social situation, they lack social grace, they are awkward and tactless, and they are intrusive and inopportune. These behaviors cause conflicts with their siblings and peers, make them unpopular, and lead to social rejection.

Deficits in this category go beyond mastering social graces, however. Children with ADD/ADHD also have difficulty following instructions. Rules are a mystery to them because:

- they are so inattentive that they do not receive information properly;
- they have difficulty processing the information they receive as instruction; or
- their impulses make it difficult for them to follow the instructions.

Rules are a set of instructions that a child is supposed to follow at home and in school. A particular house may have a rule that toys must be put away in the toy chest before bedtime. Ordinarily, after a few repetitions, this instruction would become part of a child's behavioral dictionary. Children with ADD/ADHD, however, will not be able to internalize it. They may have to be told what is expected of them again and again. This may be a nuisance and an aggravation for parents, who often perceive it as opposition and defiance.

Another deficit in social behavior for children with ADD/ADHD is the lack of both hindsight and foresight: With smaller working memories, they can neither retrieve past experience nor think about future consequences. This accounts for their failure to learn from past mistakes or to plan for the future. They live in the immediate present—moment to moment—driven by their impulses and immediate responses to external stimuli.

Aggression is yet another consequence. Children with ADD/ADHD can indulge in random acts of aggression because of impulsivity and the inability to think of the consequences of their actions. Children who indulge in aggressive acts in a deliberate and premeditated manner are likely to have conduct disorder and should be seen by a psychiatrist.

Deficits in social behavior often also cause children with ADD/ADHD to act out in order to be the center of attention. For example, Johnny is the class clown. He laughs, makes faces, grunts, and makes silly comments to get attention. If no one pays attention, he becomes louder and more obtrusive. When he is ignored, he becomes increasingly disruptive, blows on other's faces, touches them, and so on, until they pay attention.

These children also blame others for their own mistakes, are sensitive to criticism, do not accept responsibility for their actions, pout and sulk, and seek attention maladaptively, as a toddler would. For example, a child with ADD/ADHD would blame his peers for his aggressive acts: "I hit him because he was bothering me;" "I yelled at the teacher because he was mean to me." Not only are their actions driven by external contexts and contingencies—phenomena called external locus of control—their sense of responsibility is projected to others as well. They rarely accept moral responsibility for their actions.

What happens in the ADD/ADHD brain?

The neurological basis of ADD/ADHD is still not fully known. Much of the available evidence points to a deficiency or imbalance of one or more of the neurotransmitters in the brain. Neurotransmitters are chemicals that carry the message of one brain cell (neuron) to another across the tiny space between them called the synaptic cleft (see Figure 1).

Brain cells store these neurotransmitters in tiny vesicles, ready to be discharged upon command. Once discharged, they attach themselves to specific areas, called receptors, on the surface of the brain cell across the cleft. The union of a neurotransmitter with its specific receptor triggers some changes in the receiving brain cell, either stimulating it or inhibiting it. Thus, the neurotransmitters serve as the carriers of thoughts and emotions in the human brain. Once their job is done, neurotransmitters are transported back into the sending neuron, where they are repackaged as vesicles. This is a process called "reuptake."

The most popular, and perhaps the most plausible, theory of ADD/ADHD is that it occurs due to a deficiency or dysfunction of the neurotransmitter dopamine in those areas of the brain that regulate attention and activity. The exact nature of the defect is unknown. The proposed theories include defects in the synthesis, storage, release, and reuptake of dopamine, and changes in the sensitivity of dopamine receptors.

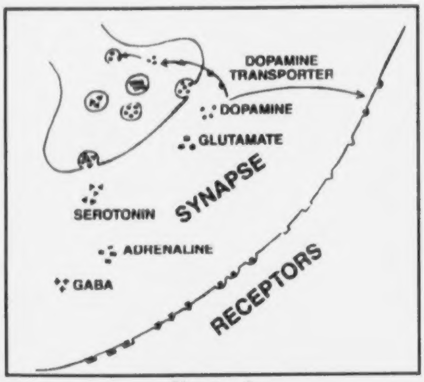

Figure 1
Neurotransmitters, such as dopamine, carry messages from one brain cell to another across the synaptic cleft.

Researchers have found abnormalities in the concentration of metabolites (waste products) of dopamine in the blood and spinal fluid of a few children with ADD/ADHD.

Regions of the brain that are involved in regulating attention are the prefrontal cortex, the caudate nucleus, the thalamus, and the nucleus accumbens. The caudate nucleus is a collection of nerve cells that lies between the cortex and the thalamus (see Figure 2) and serves as a relay station for nerve impulses. The nucleus accumbens, another collection of nerve cells, lies deeper than the caudate nucleus and is particularly rich in nerve cells that produce dopamine, the neurotransmitter whose function is implicated in ADD. There is some evidence from studies in animals that dopaminergic activity in the prefrontal cortex enhances attention and decreases motor activity. Whereas attention improves directly as a result of dopaminergic activity in the prefrontal cortex, motor activity is decreased through an inhibiting influence on the release of dopamine in the nucleus accumbens. It is thought that children with ADD/ADHD have decreased dopamine activity in the prefrontal cortex, resulting in inattention and hyperactivity. Lending support to this theory, brain-imaging techniques have shown that, in some individuals with ADD/ADHD, the right prefrontal cortex and the caudate nucleus are smaller and that there is decreased chemical activity during tasks requiring attention in the prefrontal cortex.

The prefrontal cortex is also connected to the thalamus, which serves as the relay station for all the sensory stimuli that arrive in the brain. The thalamus serves to filter the relevant or salient stimuli from noise or irrelevant stimuli and allows only the relevant stimuli to reach conscious awareness. The prefrontal cortex enhances this activity by releasing dopamine through neural pathways. In children with ADD/ADHD, this gatekeeper role of the thalamus is impaired so that every stimulus—relevant or irrelevant—reaches conscious awareness, distracting them from the work at hand.

Some researchers believe that two other neurotransmitters, noradrenaline and serotonin, are also involved in children with ADD/ADHD. The levels of methoxy-hydroxyphenylglycol, a metabolite of noradrenaline, have been reported to be low in some children with ADD/ADHD. According to some scientists, the symptoms of ADD/ADHD vary depending on which neurotransmitter system is involved predominantly: deficits in dopamine, noradrenaline, and serotonin cause the inattentive, hyperactive, and impulsive types of ADD/ADHD, respectively.

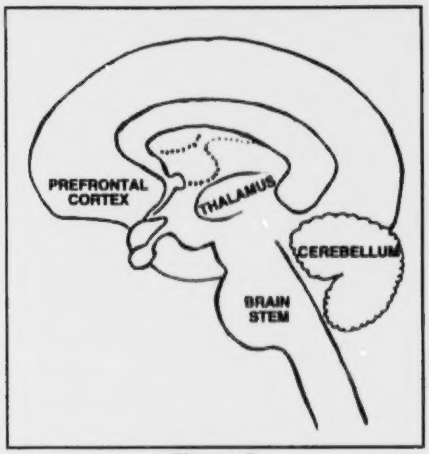

Figure 2
The caudate nucleus and nucleus accumbens lie deep in the brain between the cortex and the thalamus.

According to another group of researchers, ADD/ADHD is due to an imbalance of chemicals in the two hemisphers, (or halves) of the brain, characterized by reduced dopamine in the left half of the brain and increased noradrenaline in the right hemisphere of the brain. Because the left hemisphere is concerned with focusing attention on specific tasks, decreased function therein results in the inattentive type of ADD/ADHD. The right hemisphere is concerned with attending to a wider space, so increased noradrenaline in the right brain boosts general wakefulness and attention to unimportant stimuli in the environment, resulting in distractibility and hyperactivity. Hyperactivity occurs because the prefrontal cortex—sometimes called the managerial module of the brain—is lazy in inhibiting a hyperactive child's urge to move. Additionally, excessive noradrenergic activity puts the right brain on hyperalert, increasing distractibility.

What causes ADD/ADHD?

A diagnosis of ADD/ADHD can lead to more confusion than clarity. Parents ask, "Why us? What did we do wrong?" Conditioned to finding answers for every question, they embark on a hunt to find a cause. They blame each other; friends and family members point accusing fingers at either or both parents, the environment, the medical profession, nutritional additives or deficits, stress, popular culture, and even evil spirits that insinuate themselves into the soul. Yet, the exact cause of ADD/ADHD is still unknown.

In the 1960s, a few neurologists theorized that ADD/ADHD, like other disabling conditions such as cerebral palsy and mental retardation, was caused by minimal brain damage—not identifiable by CAT scan or MRI—sustained during the birth process. This supposition was later dismissed, since most children with ADD/ADHD have normal birth histories and most children with abnormal birth histories do not have ADD/ADHD. Major brain damage caused by such conditions as birth trauma, birth asphyxia, and traumatic head injury can be associated with ADD/ADHD. Damage to the brain is visible on the CAT scan or MRI of the brain in such cases.

Heredity: Heredity is the process by which characteristics of the parents are passed to their children—resides in genes, located in the thread-like structures called chromosomes residing in each of our cells. A number of observations suggest that heredity causes ADD/ADHD. It is five times more common for a child with ADD/ADHD to have a parent, sibling, or other first-degree relative with ADD/ADHD than it is for ADD/ADHD to occur in the general population. However, it is difficult to separate the influence of environment (nurture) from that of heredity (nature). While those with abnormal behavior share certain abnormal genes, dysfunctional relatives in the family may also set bad examples for a child to emulate.

Studies on adoption suggest that ADD/ADHD is more common in blood relatives than in adoptive relatives. This supports the case that biology is more important than environment in causing ADD/ADHD. Similarly, studies of twins report higher rates of ADD/ADHD in both identical twins (one-egg twins) than in both fraternal twins (two-egg twins), again supporting the idea of a genetically-based disease. If the cause were environmental factors, the rates of ADD/ADHD would be similar in all twins, identical or fraternal, because they share the same environment.

Despite evidence of hereditary factors in causing ADD/ADHD, an "ADD/ADHD gene" has not been discovered. Until a definite gene can be identified, only children with facial or other abnormalities suggestive of genetic conditions (such as fragile X or Williams syndrome, which often include ADD/ADHD within their own family of symptoms) should be seen by genetic disease specialists.

Environment: There is a higher prevalence of ADD/ADHD among children from low socio-economic conditions, which is perhaps due to the phenomenon of social drifting. Individuals with ADD/ADHD tend to have lower income and, therefore, move lower on the social ladder. Because of the heredity factor, they tend to bear children with ADD/ADHD. An overcrowded and disorganized environment, in turn, causes further deterioration of their condition, creating a vicious cycle. Children from homes that are poor, overcrowded, and disorganized learn to be disorganized, noisy, and loud. Distractibility and impulsivity—also hallmarks of ADD/ADHD—give them a defensive edge in a predatory environment. However, not all children who grow up in poverty turn out hyperactive and disorganized.

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Stress is another possible causative factor for ADD/ADHD including stress during pregnancy—directly, by causing pre-term birth; indirectly; or by creating a dysfunctional family environment that continues past the birth of the child. Very high levels of lead in the blood are also sometimes associated with symptoms of ADD/ADHD. A few nutritionists have found lower levels of essential fatty acids in some children with ADD/ADHD, but it is not clear if the deficiency causes the symptoms or is merely associated with ADD/ADHD by chance.

How is ADD/ADHD diagnosed?

Since there is no one fixed cause of ADD/ADHD, there are no set factors that can be identified by diagnostic tests. Diagnosis of ADD/ADHD is made clinically through parents' and teachers' reports of the child's behavior. The Diagnostic and Statistical Manual of Mental Disorders (the DSM) lists the signs and symptoms of ADD/ADHD as agreed on by a panel of psychiatrists belonging to the American Psychiatric Association.

The symptoms of ADD/ADHD fall into two categories, each with nine symptoms. The first category focuses on inattention and distractibility:

- failure to give close attention to details or making careless mistakes in schoolwork or other activities;
- difficulty in sustaining attention in tasks or play activities;
- failure to listen when spoken to directly;
- difficulty in following through on instructions from others;
- difficulty in organizing tasks and activities;

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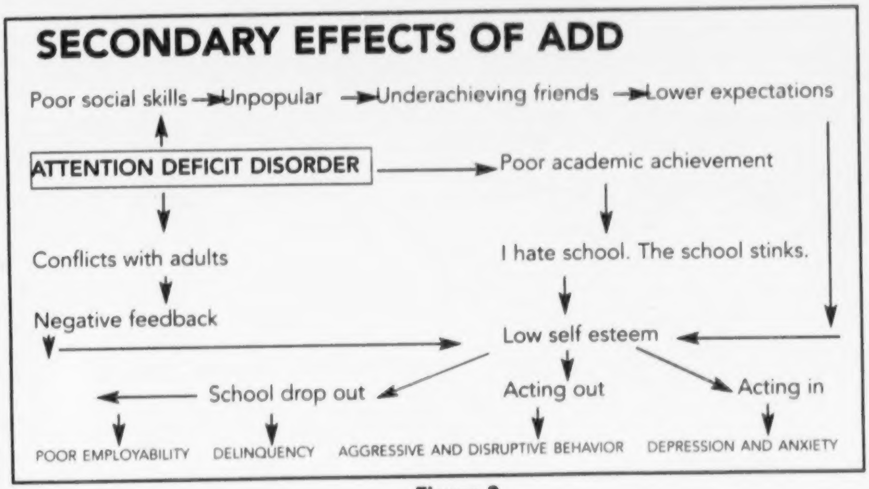

Figure 3

- avoiding tasks that require sustained mental effort (such as, schoolwork or homework);
- losing things necessary for tasks or activities;
- forgetfulness and easy distractibility.

The second category contains six symptoms of hyperactivity and three symptoms of impulsivity:

- fidgeting with hands or squirming when seated;
- subjective feelings of restlessness;
- difficulty in waiting turns in games and other group activities;
- shifting from one uncompleted activity to another;
- difficulty in playing quietly;
- engaging in physically dangerous activities without considering possible consequences;
- blurting out answers to questions before they have been completed;
- interrupting others;
- and excessive talking.

If a child has six or more symptoms in either or both of these categories, and they are considerably more frequent than in most children of the same age and intelligence, result in dysfunction at home and school, and have lasted more than six months, he or she is diagnosed with ADD/ADHD of one of three types:

- predominantly inattentive type;
- predominantly hyperactive-impulsive type; or
- combined type of ADD/ADHD.

Usually diagnosis is not attempted until after the age of 2, because 2-year-olds are generally inattentive and hyperactive. However, symptoms of ADD/ADHD generally can be observed before the age of 7.

ADD/ADHD symptoms should be observed in at least two settings, for example, school and home, for a diagnosis to be made. If the symptoms of ADD/ADHD occur only in one setting, the possibility of a situational stressor—a seriously ill parent or sibling or an impending divorce—should be considered. Similarly, if the symptoms occur with only one person, the child's relationship with that person should be considered. If a parent is experiencing depression, for example, that may influence the child's behavior.

Diagnosis of ADD/ADHD should not be made solely on the basis of the physician's observations of the child on an office visit. A medical facility is not a natural setting for a child, who may not reveal her normal behavior patterns. Parent and teacher reports and questionnaires are valuable tools for understanding a child's activities and demeanor in her regular environment. Structured questionnaires, such as the "Conners Parent and Teacher Questionnaires;" "Yale Children's Inventory;" and the "ADD/ADHD-H Comprehensive Teacher Rating Scale" (ACTeRS) provide more reliable information than the traditional medical interview, because they strip out the effects of emotion and one particular day's grueling events. These questionnaires are filled out by parents and teachers, when they are not angry or frustrated, and summarize their observations of the child over an extended period of time.

Consult a professional if you or your child's teacher suspects that your child has ADD/ADHD. Many schoolteachers are familiar with ADD/ADHD questionnaires and often use these to support their suspicion. However, the questionnaire should not be used to make a definitive diagnosis. It should serve as a signal to seek professional help. A professional familiar with the questionnaires by virtue of training in ADD/ADHD should review and score them and then make the diagnosis of ADD/ADHD after carefully excluding other possibilities. A detailed medical, developmental, behavioral, and psychosocial history should be obtained, along with a good physical and neurological examination, to rule out any treatable medical condition, to identify stressors and other diseases that may masquerade as ADD/ADHD, and to determine secondary complications and coexisting conditions. (Secondary complications of ADD/ADHD are shown in Figure 3, below). The child's, as well as the parent's, abilities and strengths should also be identified. It is important that parenting style also be assessed in order to help the parent adapt to deal with the needs of the child.

Who gets ADD/ADHD?

ADD/ADHD is an equal-opportunity disorder. It is found in all social and economic classes, from the inner city to the suburbs to the rural countryside. It is equally unconcerned with race or ethnic origin. Nor is ADD/ADHD limited to the United States—it has also been reported in the United Kingdom, Canada, Australia, Spain, and Germany. While reported less often in Europe and Australia than in the US, this may be due to physicians adhering to a more conservative approach to diagnosis

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and treatment of ADD/ADHD in those countries, as researchers working in the United Kingdom, New Zealand, Australia, and Germany, as well as in the US, have concluded. Because physicians in the US know when and how to look for it, they find it more often than their colleagues in other countries. A closer scrutiny of children's behavior in urban centers of developing countries such as China, Hong Kong, India, and Brazil, for example, has meant a steep rise in the number of children identified with ADD/ADHD.

ADD/ADHD was also once thought to favor one gender over the other. Although ADD/ADHD occurs more frequently in boys than girls (in a ratio between 4:1 and 9:1), girls are by no means immune to it. The National Ambulatory Medical Survey indicated that the diagnosis for girls increased 3.9-fold from 1990 to 1995. As girls grow older, the prevalence of ADD/ADHD increases. Diagnosis for boys starts at younger ages, but, by adolescence, it is as common in girls. Although ADD/ADHD without the hyperactivity (inattentive type) is more common in girls than in boys, the disorder is essentially similar in both genders. Girls, however, report more social difficulties than boys, perhaps because a girl's social fabric becomes more complex earlier than that of a boy.

What brings about this new surge in diagnosis in girls? Society's perspective on girls, for one, has changed. In the past, they were expected to subdue the expression of their innate nature. Traditionally, girls were taught to walk and talk softly, while their brothers were allowed to scream and stomp. They were expected to participate in more passive behaviors, such as helping mom in the kitchen or playing with dolls, while their male peers played ball in the street. Today, girls participate in all the activities the boys do, including sports and roughhouse—without parental admonishment. ADD/ADHD expresses itself earlier and more freely under such conditions. In addition, parents are now just as concerned when their daughter does poorly at school as they are when their son does not perform well. A search for the causes of academic failure can mean ADD/ADHD being diagnosed early and more often.

What can be done about ADD/ADHD?

ADD/ADHD is not a death knell for a child's academic, social, or employment future. It is, however, a wake-up call. Once ADD/ADHD has been diagnosed, the strengths and weaknesses of the child should be identified for the purpose of treatment. The ADD/ADHD label should have the sole purpose of helping the child, not to disparage him or her. Labeling should not be stigmatizing; and, last but not least, certainly should not decrease either parents' or teachers' expectations—only make them realistic.

The mind is rooted in biology. Every thought, every feeling, and every behavior has a chemical change or an electrical reaction in the brain as its base. And if the problem is chemical, it is likely its solution will be as well. Next month's segment in this special series will cover treatments to consider for children diagnosed with ADHD. ■

Dr. Gupta is an Assistant Professor of Pediatrics at the New York Medical College and a visiting associate research scientist at the Gertrude H. Sergievsky Center, College of Physicians and Surgeons, Columbia University. Certified by the American Board of Pediatrics in 1987, Dr. Gupta is a fellow of the American Academy of Pediatrics. He serves on the organization's Project Advisory Committee of Medical Home Initiatives for Children with Special Health Care Needs. He is known in print through his book, Manual of Developmental-Behavioral Problems on Children, and scholarly articles in publications such as Pediatrics, the American Journal of Clinical Epidemiology, Indian Pediatrics, The Record, and Weber Studies.

RESOURCES

AD-IN:
Attention Deficit
Information Network
475 Hillside Ave.
Needham, MA 02494
Telephone:
(781) 455-9895
E-mail: adin@gis.net
Web site: http://www.addinfonetwork.com
AD-IN offers support and information to families of children with ADD, adults with ADD, and professionals through a network of AD-IN chapters.

Children and Adults with Attention Deficit Disorder (CHADD)
8181 Professional Plaza
Ste. 201
Landover, MD 20785
Telephone:
(800) 233-4050
E-mail:
national@Chadd.org
Web site:
http://www.Chadd.org
CHADD works to improve the lives of people with attention-deficit/hyperactivity disorder through education, advocacy, and support.

CHADD-Canada, Inc.
1376 Bank St., Ste. 214
Ottawa, ON, Canada
K1H 1B3
Telephone:
(301) 306-7070
E-mail:
chaddcanad@hotmail.com
Web site:
http://www.members.tripod.com/~chadd-canada/index.html
Chadd Canada is a non profit parent run organization that aims to help support, educate, and ultimatly better the lives of individuals with ADD and of those who care for them.

Learning Disabilities Association of America (LDA)
4156 Library Rd.
Pittsburgh, PA 15234
Telephone:
(412) 341-1575
The purpose of the Learning Disabilities Association of America is to advance the education and general welfare of children and adults of normal or potentially normal intelligence who manifest disabilities of a perceptual, conceptual, or coordinative nature.

National Attention Deficit Disorder Association (NADDA)
1788 Second St.,
Ste. 200
Highland Park, IL 60035
Telephone:
(847) 432-ADDA (2332)
E-mail: mail@add.org
Web site:
http://www.ADD.org
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Westmont, IL 60559
800-432-6435 fax: 630-655-0391
info@angelman.org
www.angelman.org

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What is Angelman Syndrome?

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organizational spotlight

The President's Committee on Mental Retardation

When John F. Kennedy entered the office of the Presidency, no federal programs existed that addressed the needs and interests of people with mental retardation. Inspired by personal experience (his sister, Rosemary, has mental retardation), President Kennedy created a President's Panel on Mental Retardation in 1961 to advise him on how the federal government could best meet the needs of this neglected population. Emanating from that panel was a research agenda placed under the auspices of the newly created National Institute on Child Health and Human Development.

Many of the field's most distinguished professionals and advocates serve on the President's Committee on Mental Retardation.

In the following administration, President Johnson formally chartered the President's Committee on Mental Retardation (PCMR), and the Committee has served every president since in an advisory capacity.

Many of the field's most distinguished professionals and advocates served on the PCMR, most notably the incomparable Dr. Elizabeth M. Boggs. Dr. Boggs, a physicist who gave birth to a son with profound mental retardation, initiated the Facilities Construction Act, which provided funds for service programs throughout the states, many for the first time. PCMR recommendations led to the formulation of the developmental disabilities concept and established the national network of programs we have all come to depend upon: University Affiliated Programs, Developmental Disabilities Councils, and Protection and Advocacy Systems.

The President's Committee charter incorporates prevention as a keystone of its mission. Promoting healthy pregnancies, immunizations, child safety, and early interventions for infants and toddlers remain at the core of PCMR initiatives.

•PCMR conducted National Collaborative Academies on Mental Retardation, inviting the governors of the states to appoint teams to come to Washington, D.C. for intensive immersion in best practices and policy issues. Over five years, teams from 40 states and Native American tribes participated in the academies and developed action plans for inclusion. The 1999 academy even hosted a delegation of 17 team members from Great Britain! As a result, Louisiana has replicated the experience in state academies for the past five years; the Navajo Nation held a Four Corners Academy bringing tribes together in the Southwest; a long-standing deinstitutionalization lawsuit was successfully resolved; and waiting list legislation appropriated funds for new community supports and services in several states.

•PCMR, in collaboration with the Reaching Up Foundation, created the National Alliance of Direct Support Professionals. The goal of this organization is to promote the quality of life and educational opportunities for frontline workers in human services, a key to successful life in the community for citizens with intellectual disabilities. That collaboration continued in the publication of "Opportunities for Excellence," which deals with quality direct support, and a five-part series, *With a Little Help From My Friends* (full text available free at http://www.acf.dhhs.gov/programs/pcmr).

•Another strategy PCMR employed for developing the workforce was the initiation of a national conference for emerging young leaders in the field aged 35 and under. "The Next Generation of Leadership Symposium" will bring young people with disabilities, young parents, direct support professionals, educators, agency administrators, advocates, elected officials, researchers and all other interested parties to Washington this summer for the fifth year in a row. Entitled the "Millennium Summit," the conference will focus on learning skills in collaboration, behavioral support and quality assurance, and will examine emerging policy issues of the new century.

•Those who have mild cognitive disabilities (I.Q. 70-85) were the subject of PCMR's 1999 conference, "The Forgotten Generation Summit" held this past February.

What "The Forgotten Generation Summit" struggled to grasp was the extreme vulnerability of people with mild cognitive limitations. Living at the margins of society, many of these individuals maintain a normal lifestyle, blending into the larger population of what may be regarded as "the working poor." It is when crisis strikes that life becomes dangerous: an unexpected pregnancy, a criminal attack, sudden illness or injury, divorce or abandonment, even a missed utility bill may spell disaster. With limited intellectual resources and impaired judgement, those with mild cognitive impairments may suffer extreme consequences in circumstances that for others would merely constitute a patch of bad luck.

In many ways, those who are the most nearly "normal" are actually at the greatest risk: the mental retardation is so mild that they do not qualify for special education services, or may be misdiagnosed and receive inappropriate educational services. Unsupported, they are likely to fail in school, and are at high risk of dropping out, getting pregnant, getting in trouble, or becoming addicted to alcohol and drugs. Generic service systems and institutions do not recognize them as having disabilities and tend to place expectations upon them they cannot meet without specialized supports.

•On its own initiative, PCMR sought and found a means of addressing our overlapping interests in prevention, early intervention, education, employment and criminal justice. PCMR, in cooperation with the Reaching Up Foundation of New York and the City University of New York, and in partnership with the Office of Child Support Enforcement, sponsored a major conference called "Poverty and Disability: A Call to Action," held on February 22-23, 2000, in New York City. Over 400 individuals participated in the conference representing 35 US states, Puerto Rico, 10 Native American tribes, Jamaica, Haiti, and Japan. The conference served to raise consciousness among community service, health and law enforcement agencies about the prevalence of mild and often hidden cognitive disabilities within their client populations, and to foster effective grass-roots collaborations among non-traditional partners in addressing individual needs for specialized services and supports.

Building bridges with human service agencies of all types is the most important work that PCMR sees for itself in the contemporary realm. As people with mental retardation experience fuller, richer lives in the community, agencies with their special interests and with special skills in working with them are obliged to become better partners with established community institutions. Schools, daycare centers, grocery stores, churches and synagogues, insurance companies, and law enforcement agencies need to recognize, appreciate and support our sons and daughters as they boldly move into the future. ■

For more information on the President's Committee on Mental Retardation, contact them at:

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Circle #25

familiar faces

KYMBERLI

Kymberli Bowser, 6, dances the night away with her partner, grandfather **Paul Fleschl** Kymberli, who has spastic diplegic cerebral palsy, attends Miriam Morris Private School in Hamilton Township, NJ. She likes to play baseball, swing on her swing-set, eat pizza, and watch her favorite TV shows, Blue's Clues, Franklin, and Little Bear. Her favorite singer is Shania Twain. Kymberli lives with her mom, Beverly, in Hamilton Township, NJ.

ASHLEY

Ashley Becker, 13, is ready for her first day at school! Ashley has mild mental retardation and low muscle tone. Because Ashley and her family live in a very small community, she travels 20 miles to a special-education morning program, and goes to her public school in the afternoon. Ashley is involved in Girl Scouts and 4-H. She also enjoys swimming, riding her bike, and playing games with her sister, Kayla, 9. Ashley and Kayla live in Exeter, NE, with their older brother, Chase, 15, their parents, Mark and Meg, their dog, Jiggs, and numerous cats.

DANIELLE

Danielle Marie Zarro, 5, looks curious! Danielle has Down syndrome and attends preschool three mornings a week. She enjoys roller blading, reading, and playing with her brother, Jeremy, 20 months, and sister, Colleen, 7. Danielle loves to watch RugRats on TV, and eat her Grandma's macaroni and meatballs! She and her siblings live in Clinton, CT, with their parents, Ron and Elaine.

Would you like to share a favorite candid snapshot or slide of your child and/or family with other readers of Exceptional Parent? Send it to: Readers' Photos, *Exceptional Parent*, 555 Kinderkamack Road, Oradell, NJ 07649-1517. (Please do not send originals or "one-of-a-kinds" as we regret that **photos cannot be**

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JORDAN & GABRIELLE

Twice as nice! **Jordan Edward Arispe** and sister **Gabrielle Raquel** are 2-year-old twins. Both have cerebral palsy and receive physical, occupational, and speech therapies. Jordan enjoys listening to music and throwing balls around. According to her mom, Marisol, Gabrielle's favorite activity is eating ice cream with her grandpa! The twins live with their mom and dad, Richard, in Corpus Christi, TX.

KYLIE

Kylie Hannah Dean, 3, is sitting pretty! Kylie has cerebral palsy and attends a special preschool at Ocotillo Elementary School. She loves socializing with other children, listening to music, and fingerpainting. She also enjoys having visits from her grandparents and playing with her two dogs, Barkley and Mattie. Her favorite TV shows are Barney, Elmo, and Blue's Clues. Kylie lives in Palmdale, CA, with her mom, Laura, and her dad, Dennis.

TAYLOR

Taylor Leigh Jackson, 3, and her mom, **Amy**, share a laugh! Taylor, who was born three months premature, has cerebral palsy. Although Taylor has trouble with balance and coordination and can walk only with support, her mom says she is getting stronger every day. Taylor enjoys going to school, singing, and riding her pony and four-wheeler. She also loves water and animals. According to Amy, Taylor is a smart little girl who talks all the time! Taylor lives with her mom, and dad, Jeremy, in Grafton, WV.

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returned.) On a separate sheet of paper, write your child's full name, age at the time the photo was taken, address and daytime phone number. Please identify everyone in the photo. If you like, you can also write a few sentences about your child. Then look for a familiar face in an upcoming issue!

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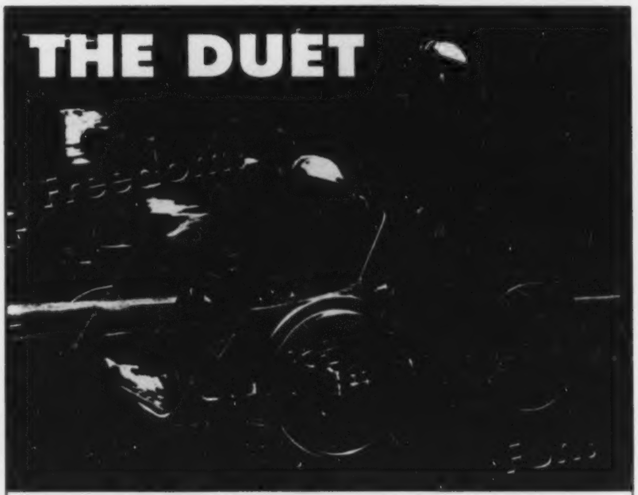

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Circle #32

Special Report — PART ONE

NEWBORN SCREENING

Testing for Disorders at Birth

by Fern R. Potvin

Newborn screening—testing infants for certain genetic anomalies, inborn errors of metabolism, and other disorders—has been commonplace since the 1960s but has rarely been a topic for public discourse. Within the last year or two, though, newborn screening has become of interest not only to healthcare professionals and scientific researchers, but to a far broader audience.

Articles in such publications as the *Philadelphia Enquirer*, *US News and World Report*, and *The New York Times* have explored the subject of screening. The *Morbidity and Mortality Weekly Report*, a publication of the Atlanta-based Centers for Disease Control and Prevention, reported on data from Georgia's screening program. The Maternal and Child Health Bureau (part of the federal Health Resources and Services Administration) and the American Academy of Pediatrics (AAP) have convened a task force on newborn screening to update the AAP's 1996 guidelines. The initial report is expected within the next few months. Many state legislatures are reexamining their current programs and debating expansion of testing requirements. The almost-complete Human Genome Project is expected to prompt still further discussion of issues surrounding testing for errors of metabolism and genetic disorders.

In this three-part Special Report, EP will explore newborn screening and its ramifications. We begin this month with an overview of newborn screening: history, the state of the art, and brief descriptions of the most commonly tested disorders in the United States today.

OVERVIEW

In 1963, Massachusetts became the first state to mandate screening for a genetic disorder. A test developed in 1961 by Dr. Robert Guthrie of the University of Buffalo identified **phenylketonuria (PKU)***, an inherited condition that, if left untreated, causes severe mental retardation. The National Association for Retarded Children, the Children's Bureau, and the Kennedy Foundation were among the organizations that pushed for widespread adoption of the Guthrie test for PKU, which is now mandated by all 50 states and the District of Columbia.

Dr. Guthrie's work in the field of mental retardation led him to develop tests for **galactosemia**, **maple syrup urine disease (MSUD)**, and **homocystinuria**. Ongoing research in disciplines including cell biology, biochemistry, enzymology and genetics (aided by increasing sophistication of techniques such as electron microscopy, chromatography, and spectrophotometry) enabled development of tests for **congenital hypothyroidism**, **biotinidase deficiency**, **congenital adrenal hyperplasia**, and **hemoglobinopathies** such as sickle cell disease. Screening for hypothyroidism, like PKU, is now mandated throughout the US, and the test for galactosemia is required everywhere but Louisiana, Pennsylvania, and Washington state. Tests for other disorders—**cystic fibrosis**, **tyrosinemia**, **toxoplasmosis**, **MCAD**, **G6PD**, and **HIV**—are required by only a few states. (The accompanying Table displays mandatory newborn screens by state, plus some tests performed by special request only, which are marked "SR.")

WHY SCREENINGS HAVE NOT ALWAYS BEEN PERFORMED

Although it would seem logical to screen all newborns for every possible disorder, there are several reasons why this has not been so.

1. Problems with testing methodology. The Guthrie test, based on a blood spot on filter paper from a heelstick (a method of obtaining blood samples from newborns by pricking the heel) and bacterial assays (tests), required a separate test for each disorder although the same blood spot could be used. Results were generally not available prior to the infant's discharge from the hospital. Some conditions, such as hypothyroidism, initially required urine samples to be tested through chromatography, and it was found that specimens needed to be collected seven or more days after birth to give true readings. There was often considerable difficulty in obtaining samples for tests because most newborns were no longer in the hospital.

2. Difficulty providing necessary follow-up and counseling. Many conditions required long-term monitoring, follow-up testing, and parental counseling. The frequency with which many families change residences and insufficient manpower at medical facilities made it difficult to track and counsel families,

continued on page 93

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*See glossary for boldface words.

Sponsored in part by an unrestricted grant from Sigma Tau Pharmaceuticals, Inc.

GLOSSARY

Phenylketonuria (PKU). This metabolic condition results from the lack of an enzyme in the liver that converts phenylalanine to tyrosine. Phenylalanine is one of the essential amino acids found in all protein foods. Incidence is 1:12,000 and although it is found in all ethnic groups, PKU is most prevalent among people of Irish or Scottish descent. Symptoms include severe mental retardation, seizures, autism-like disorders, and a peculiar odor. Lifespan is reduced. Treatment consists of lifelong dietary management and counseling.

Galactosemia. This is an inherited disorder of galactose metabolism. Galactose is the major sugar found in milk. Incidence is 1:50,000 and has no reported ethnic or racial variability. Symptoms include severe mental retardation, overwhelming systemic infections, failure to thrive, vomiting, liver disease, and cataracts. Untreated galactosemia is generally fatal. Treatment requires elimination of milk and milk products (all products containing lactose) from the diet.

Maple syrup urine disease (MSUD). MSUD is caused by abnormal metabolism of three branched-chain amino acids: leucine, isoleucine, and valine. Although the overall incidence of the disorder is 1:200,000, it is about 1:760 among Mennonites. Symptoms include an odor of maple syrup in the urine, poor feeding, lethargy, coma, and mental retardation. If not treated, death commonly occurs within three months of birth. Treatment requires dietary restriction of branched-chain amino acids, necessitating a complicated formula and intensive monitoring.

Homocystinuria. The most common cause of homocystinuria is a deficiency in the enzyme cystathionine ß-synthase. Incidence is 1:200,000, but prevalence is 1:82,000 in Great Britain, Ireland, and Australia. Among the symptoms are thromboembolism, optic lens dislocation (which may occur even with treatment), scoliosis, osteoporosis, mental retardation, seizures, and psychiatric disturbances. Approximately 50 percent of untreated individuals die before age 25. Treatment may include a methionine-restricted, cystine-supplemented diet, as well as large doses of Vitamin B6.

Congenital hypothyroidism. This disorder is caused by inadequate production of thyroxine, a thyroid hormone. Incidence is approximately 1:4,000. Symptoms include mental retardation, growth failure, deafness, neurologic abnormalities, and slow metabolism. Treatment is levothyroxine, thyroid hormone replacement therapy, given orally.

Biotinidase deficiency. A deficiency of biotin, part of the Vitamin B complex, leading to multiple carboxylase deficiency. Incidence is 1:87,000. Symptoms include seizures, hypotonia, immune system impairment, skin rashes, hair loss, hearing loss, and mental retardation. Treatment is oral biotin supplementation.

Congenital adrenal hyperplasia (CAH). The most common form (more than 90 percent of all recognized cases) results from 21-hydroxylase deficiency. Incidence is 1:12,000, but may be as high as 1:5,000 among those of Italian background. CAH causes increased androgen production, resulting in ambiguous genitalia and virilization in girls and early virilization in boys. Other symptoms are accelerated skeletal maturation and ultimate short stature. Treatment is glucocorticosteroids.

Hemoglobinopathies. A group of disorders characterized by abnormal hemoglobin ß chains: sickle-cell disease and thalassemia are two. Overall incidence of hemoglobinopathies in the US is 1:58,000. Sickle cell is most commonly found in African-Americans and has an incidence of about 1:600. Thalassemia is most likely to affect people with eastern Mediterranean (Greek, Arabic, Italian) or East Indian ancestry. Symptoms are lifelong hemolytic anemia, abnormally shaped blood cells leading to acute and chronic tissue damage, intermittent cardiac crises, enlarged spleen, and sepsis. Ongoing therapy is penicillin prophylaxis and vigilant treatment of infections. Aggressive pain management, management of dehydration and acidosis, blood transfusions, and oxygen are all utilized for acute episodes.

Cystic fibrosis. An inherited disorder that affects the mucus-producing glands. Mucus is thick, and can obstruct air passages in the lungs. It also causes dysfunction of the sweat and salivary glands, and blocks the enzymes secreted by the pancreatic duct, resulting in incomplete digestion. Incidence is 1:2,500 white live births and 1:17,000 African American live births. Cystic fibrosis can cause lung disease, failure to grow, clubbed fingers and toes, muscular weakness, and visual impairment. Treatment includes high doses of ibuprofen, antibiotics for pulmonary disease, and clearing of the airways with intermittent aerosol therapy.

Tyrosinemia. A metabolic disorder that causes elevated levels of tyrosine, an amino acid present in most proteins. The incidence is 1:100,000 live births, with both sexes affected equally. Symptoms include failure to thrive, vomiting, diarrhea, and a cabbage-like odor. Other symptoms include enlarged liver, edema, and risk of hemmorhagic diseases. If untreated, tyrosinemia is fatal within the first year of life. Treatment includes dietary restrictions.

Toxoplasmosis. An infectious disease that, if it occurs congenitally, can cause severe fetal disease. The incidence of congenital toxoplasmosis is 0.25:100,000 to 5:100,000 live births. Symptoms can include microcephaly (small head size), hydrocephalus, vision impairment, mental retardation, seizures, anemia, jaundice, and rash. Treatment, when indicated, includes antibiotics such as pyrimethamine and sulfadiazine.

MCAD. Medium-chain Acyl-CoA dehydrogenase (MCAD) deficiency is an inherited enzyme deficiency. The incidence is 1:50,000 live births, with males and females affected equally. Symptoms include intermittent hypoglycemia and metabolic acidosis, sometimes resulting in coma. Fatty changes in the liver may also occur. Treatment involves prevention of prolonged fasting to prevent symptoms.

G6PD. Glucose-6-phosphate-dehydrogenase (G6PD) is an enzyme that is necessary for glucose metabolism and the preservation of red blood cells. G6PD deficiency is the most common genetic enzyme deficiency, occurring most often in tropical and subtropical Asia, tropical Africa, areas of the Mediterranean, the Middle East, and New Guinea. It can cause premature destruction of red blood cells (hemolytic anemia) when an affected individual is exposed to certain medications, chemicals, foods, or pollen. Severity of the condition is extremely variable. Treatment involves restricting exposure to pathogens that cause a reaction.

HIV. Human immunodeficiency virus (HIV) is an immunosuppressive disorder resulting from viral infection and destruction of the body's T-cells. The virus eventually progresses to acquired immunodeficiency syndrome (AIDS). Incidence in newborns varies according to viral status of the mother. Initially, HIV is asymptomatic. Young children, however, have a much shorter incubation period and generally develop symptoms within two years. Symptoms include wasting, fatigue, fever, oral thrush, rashes, and superinfection with opportunistic organisms. Treatment involves chronic use of antiviral drugs to slow progression of the virus and allow the immune system to recover. Infections are treated with antibiotics and antifungals.

TABLE: Newborn Screening by State

State	Phenylketonuria	Hypothyroidism	Galactosemia	Maple Syrup Urine Disease	Homocystinuria
Alabama	X	X	X		
Alaska	X	X	X		
Arizona	X	X	X	X	X
Arkansas	X	X	X		
California	X	X	X		
Colorado	X	X	X		
Connecticut	X	X	X	X	X
Delaware	X	X	X		
D.C.	X	X	X	X	X
Florida	X	X	X		
Georgia	X	X	X	X	X
Hawaii	X	X	X	X	
Idaho	X	X	X		
Illinois	X	X	X		
Indiana	X	X	X	X	X
Iowa	X	X	X	X	
Kansas	X	X	X		
Kentucky	X	X	X		
Louisiana	X	X			
Maine	X	X	X	X	X
Maryland	X	X	X	X	X
Massachusetts	X	X	X	X	X
Michigan	X	X	X	X	
Minnesota	X	X	X		
Mississippi	X	X	X		
Missouri	X	X	X		
Montana	X	X	X		
Nebraska	X	X	X		
Nevada	X	X	X	X	
New Hampshire	X	X	X	X	X
New Jersey	X	X	X		
New Mexico	X	X	X		
New York	X	X	X	X	X
North Carolina	X	X	X		
North Dakota	X	X	X	X	
Ohio	X	X	X		X
Oklahoma	X	X	X		X
Oregon	X	X	X	X	
Pennsylvania	X	X		X	
Rhode Island	X	X	X	X	X
South Carolina	X	X	X		
South Dakota	X	X	X		
Tennessee	X	X	X		
Texas	X	X	X		
Utah	X	X	X		
Vermont	X	X	X	X	X
Virginia	X	X	X	X	X
Washington	X	X			
West Virginia	X	X	X		
Wisconsin	X	X	X		
Wyoming	X	X	X		
TOTAL COUNT	**51**	**51**	**48**	**20**	**15**

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Biotinidase Deficiency	Adrenal Hyperplasia	Other	Hemoglobin-opathy
	X		X
X	X		
X			X
			X
			X
X	X	CF	X
X	X		X
			X
		G6PD	X
	X		X
	X	Tyrosinemia	X
X	X		X
X	SR*	SR: Leucine	SR
X	X		X
			X
	X		X
			X
			X
X			X
X	X	MCAD	SR
X		Tyrosinemia	X
X	X	MCAD; CF; others	X
X	X		X
	X		X
			X
			X
		SR: CF	
X			X
X			X
		Toxoplasmosis	random
			X
X	X		X
X		HIV	X
	X		X
	X		
			X
			X
X	X		X
			X
X	X		X
	X		X
			SR
			X
	X		X
X			X
X			X
	X		X
			SR
X	X	CF	X
X		CF	X
22	**23**	**12**	**47**

Newborn Screening

continued from page 90

secure specimens for follow-up tests and monitor treatment. If the child was asymptomatic, parents could be resistant to counseling, ongoing tests, and perceived "interference" from the state.

3. No available treatment. Because none of these conditions is curable, they might not be screened for. Some, such as PKU, are treatable with highly restrictive diets; others, such as HIV, require exacting and expensive drug regimens. Support, both emotional and financial, can be problematic.

4. Limited resources. Some states perform all tests in state laboratories; in others, some tests might be referred to private labs. Smaller states have created regional coalitions for testing of some disorders. Cost of testing is an ongoing issue; if each disorder requires a separate test, lab fees can add up quickly. Responsibility for payment and allocating costs has only become more complicated by managed care. Staffing needs, both for labs and for counseling and follow-up, grow as tests are added, requiring higher payrolls.

5. Rarity of disease. Incidence of these conditions might range from 1:1,400 (hemoglobinopathies) to 1:150,000 (homocystinuria) live births, and might further vary by race and ethnicity. State population and demographics might suggest that routine screening for some disorders would be unproductive.

A BRIGHTER HORIZON

Several of the reasons for limits on mandated screening will, in some form, always remain part of the debate. A radical change in treatment methodology, however, is redefining one argument, changing the terms of others, and fostering reexamination of newborn screening.

Tandem mass spectrometry (MS/MS) is a powerful and extremely sensitive testing tool, with the ability to use one test for many disorders. MS/MS can identify approximately 30 different conditions from one or two heelsticks performed within 24 hours of birth, and reduces the rate of false-positive results seen with traditional testing methodologies from about 1.5 percent to about 0.26 percent. However, the equipment is costly and highly specialized training is required to read test results. There are only a few MS/MS facilities in the US. ■

Next month's article will cover the medical aspects of screening in greater detail, including sources for performing tests, disorders that can be identified through screening, and types of treatment available for various groups of disorders. In October, look for coverage of other aspects of screening, including privacy concerns, public-health questions, and economic implications.

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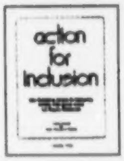

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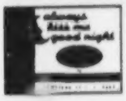

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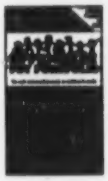

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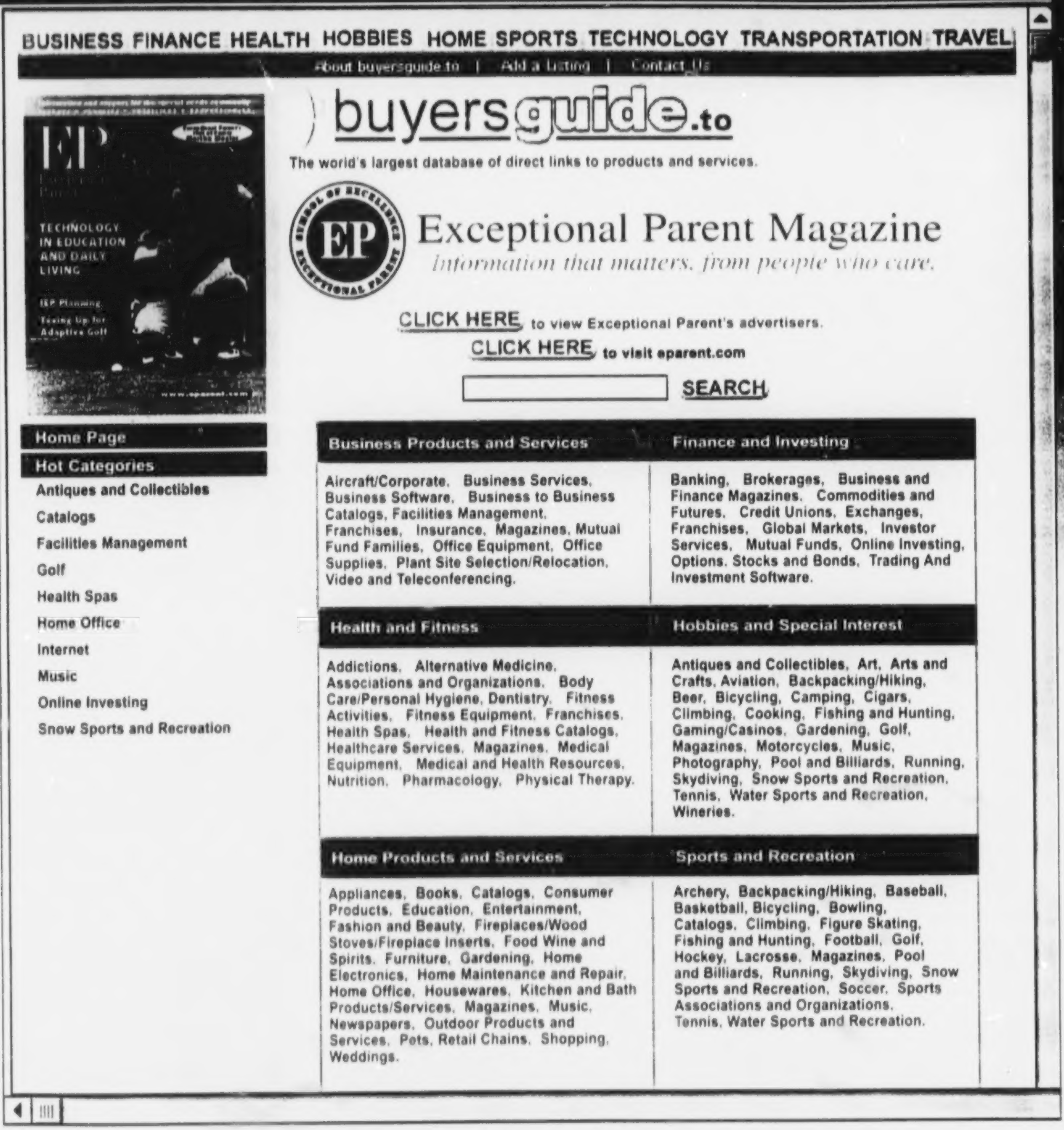

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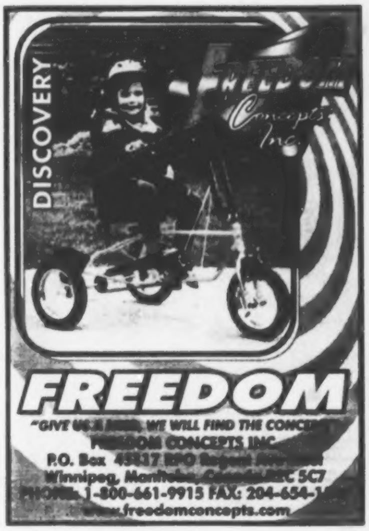
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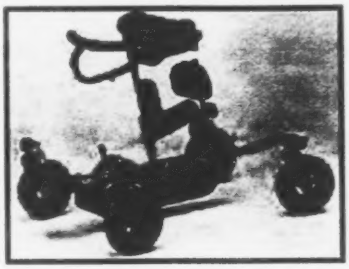

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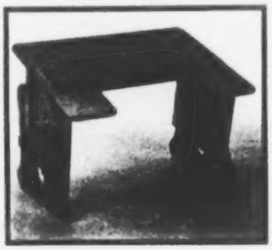

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The ABLEDATA database of assistive technology and rehabilitation equipment contains information on more than 25,000 products for persons of all ages who have a physical, cognitive, or sensory disability. Products are chosen for this page by the ABLEDATA staff based on their specific applicability to or design for children who have disabilities. ABLEDATA, operated by Macro International Inc., is funded by the National Institute on Disability and Rehabilitation Research under contract number HN-96015001.

For more information on these and other assistive devices, or to submit product information for the database (and possible inclusion on this page), contact: **ABLEDATA, 8630 Fenton St., Ste. 930, Silver Springs, MD 20910; (800) 227-0216 or (301) 608-8998 (voice); (301) 608-8912 (TTY); (301) 608-8958 (fax); Web site: http://www.abledata.com.**

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"Hippie Dippy"

by Jesse Ferencz

Do you know someone with Rett Syndrome? I do—my 5-year-old sister Nikki. (Rett syndrome is a degenerative genetic disorder that is behaviorally similar to autism and leads to physical and mental retardation.) Nikki can walk, but she wears splints in her shoes to help her walk better. She loves to be around people. When someone makes a joke, Nikki will laugh right along with everyone.

Jesse (left), 10, always sticks by her sister Nikki, 5.

Nikki loves to be read to. Her favorite books are: *If You Give A Mouse A Cookie*, and *If You Give A Pig A Pancake*. One night, Nikki, Pepper (our babysitter), and mom, and I were at a restaurant, and we made up a story that goes like this: If you give Nikki a menu she will always take a bite out of it. If she takes a bite out of it that will be her dinner. If that's her dinner she will want to go home and go to bed. If she wants to go to bed she will want her bottle, and she will want you to read her a story. If you read her a story, chances are she will want you to read, "If you give Nikki a menu." The story made us all laugh.

Nikki likes to swim, too. We have a swimming pool in our backyard and go swimming all summer. When we get her to kick her feet, before you know it, she's gliding across the pool!

Once in a while, we go bowling. Nikki sits on the floor and we set the bowling ball in her lap. She gives it a push down the lane; I've never seen her get a strike, but I know she will some day!

Sometimes we play the tickle game, too. I get to tickle her, but she can't tickle me back. She loves it anyway.

Pepper came when I was just in first grade, and she is still with us to this day. She is like an older sister to Nikki and me. Pepper takes us out for lunch, shopping, and she plays crazy games that Nikki can be a part of. We always end up on the floor laughing.

Despite her limited speaking skills, Nikki is never short of smiles.

Nikki has taught me that no one is perfect and everyone is different. It wouldn't be fun if everyone was the same.

She can say some words like: "mom," "dad," "Pepper," and "want more." She tries to say other words, but they don't come out right. She has a touch computer to help her communicate. When you touch one of the icons it will say something like, "I need a break." I help program the computer by recording my voice so that we hear a kid's voice when she touches an icon to speak.

Even though she can't talk very well there is a phrase she uses very often. It doesn't mean anything, but we know she is happy when she smiles and says, "hippie dippy." ■

Jesse and Nikki live with their mom Karen and dad Jeff in Garrison, NY.

MOM'S TURN

Nikki's sister Jesse.

Karen Ferencz says she is proud of her two daughters and their relationship. "Jesse has always been a terrific sister to Nikki. She knows Nikki's medicine schedule, her therapy schedule, what food she can and cannot eat, and can calm Nikki down when she is agitated. She can also get Nikki to laugh great big belly laughs when she is sad." Karen also credits the girls' babysitter Pepper for her positive contribution in working with Nikki on some of her therapies. "I feel very lucky to have her in our life."

The Children's Page welcomes contributions from children who have disabilities, their siblings, and their friends. Be creative! Send your stories, photos and/or artwork to: Children's Page, EXCEPTIONAL PARENT, 555 Kinderkamack Road, Oradell, NJ 07649-1517. Be sure to include your name, address, and day-time telephone number! Now on the Web! We will now be including **Familiar Faces** and **Children's Page** on our Web site, www.eparent.com. Please send us your photographs with the understanding that doing so gives Exceptional Parent permission to put the photos on the Exceptional Parent Web site, exactly as they appear in the magazine and with the same text.

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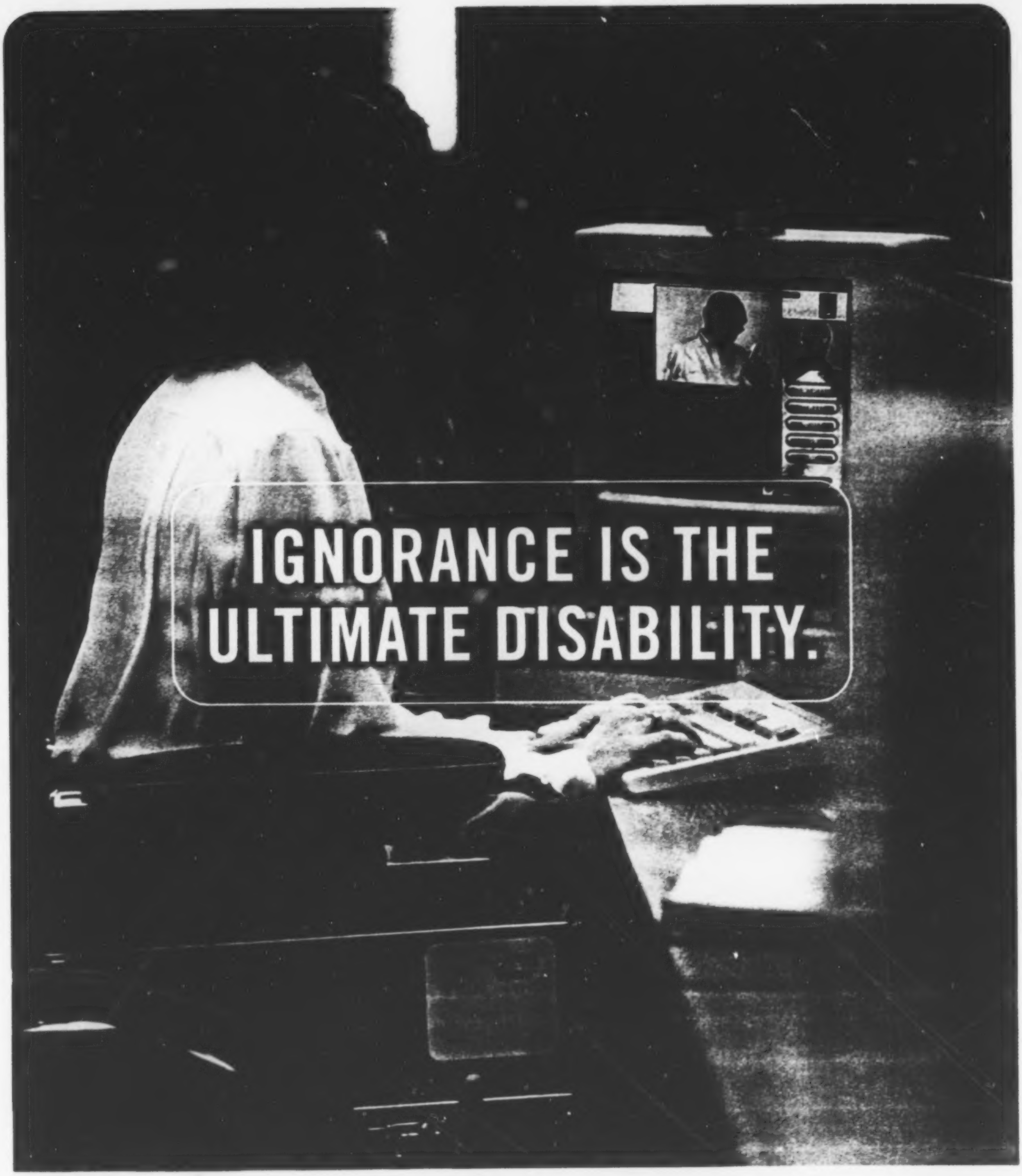
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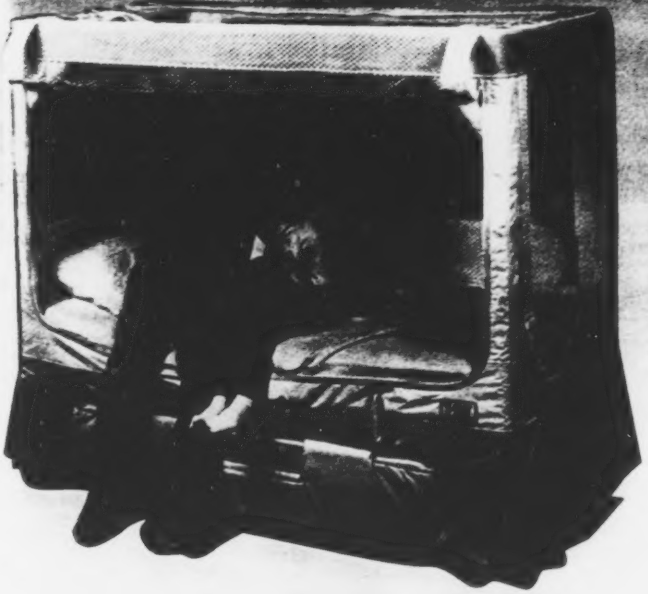

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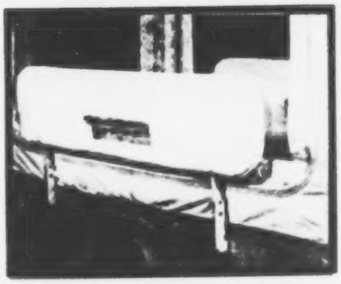

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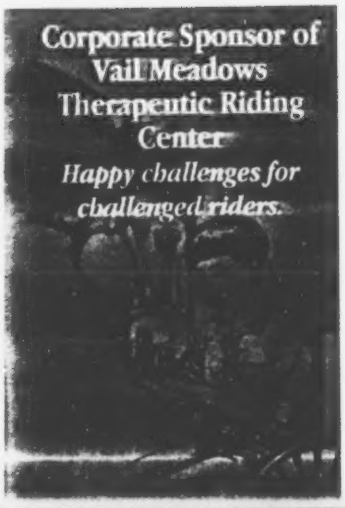

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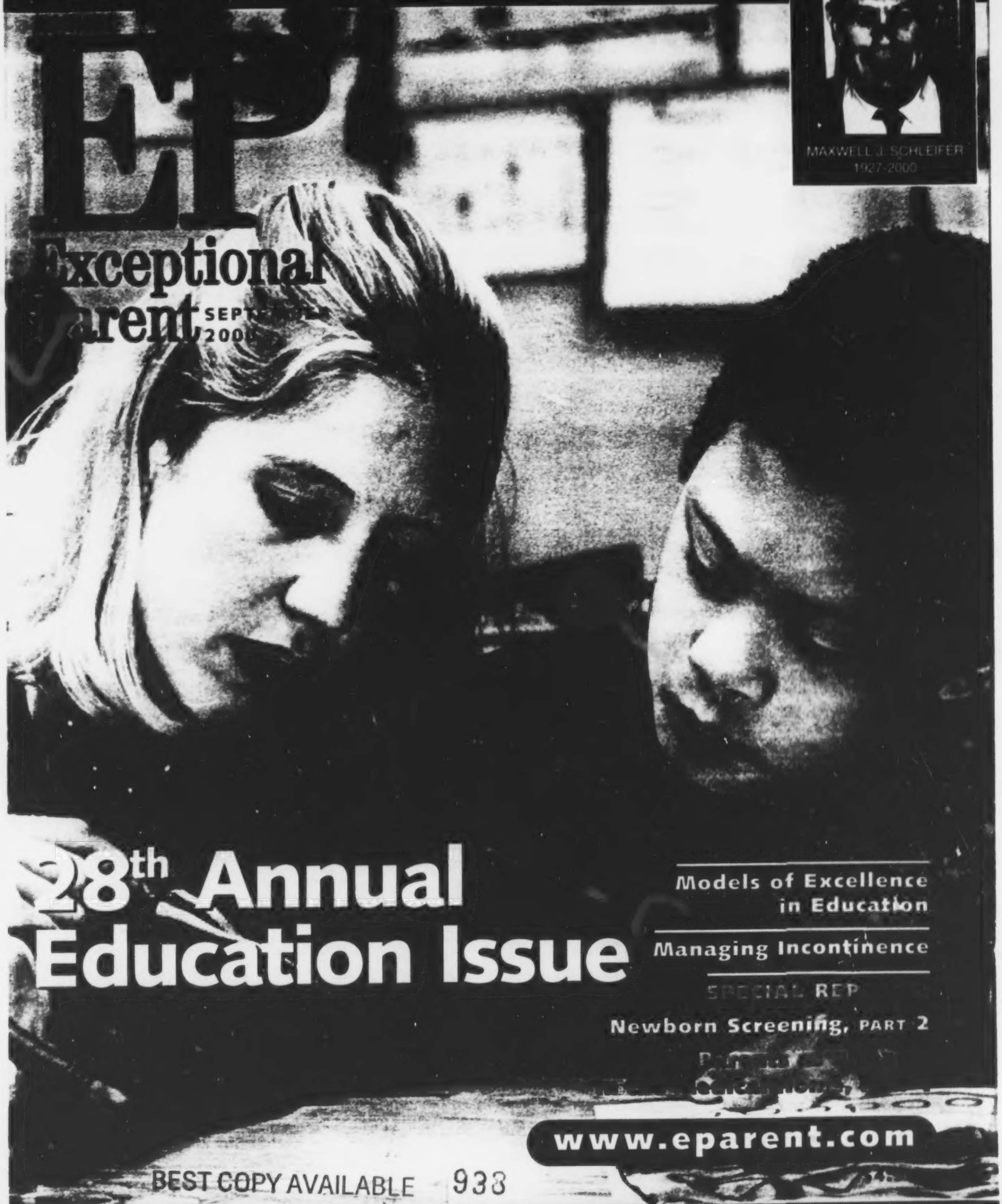

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28th Annual Education Issue

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Managing Incontinence

SPECIAL REP

Newborn Screening, PART 2

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Annual Listing of Schools, Camps, and Residences

At The New England Center for Children

each child's independence

is at the center of our attention.

There are many reasons why children come here, from all across the country, to The New England Center for Children.

They come for our nationally recognized educational, residential and treatment programs — all community based, all offered from one source. As a center of excellence, our efforts focus not on expanding into multiple locations, but on perfecting programs that will expand children's lives.

They come for our professional staff. Many are nationally known in the fields of autism and applied behavior analysis; all bring a special warmth and enthusiasm to everything from our preschool to our adolescent programs. Bringing to every child — your child — unwavering commitment. Each and every day.

They come and participate in services that range from intensive speech and language programs, to adaptive physical education, to employment training, to management of behavior problems.

And when, in time, each child leaves, individual potential has been reached, a new level of independence achieved.

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At NECC, we welcome children diagnosed with autism, behavior disorders, learning disabilities, language delays, mental retardation and related disabilities. Nationally recognized for the success of our programs, we are equally well known for our dedication — on every level — to bringing about positive change in the lives of the children who come here. Change that helps them live more productively and independently, long after they leave.

The New England Center
FOR CHILDREN
Independence through Educational Excellence

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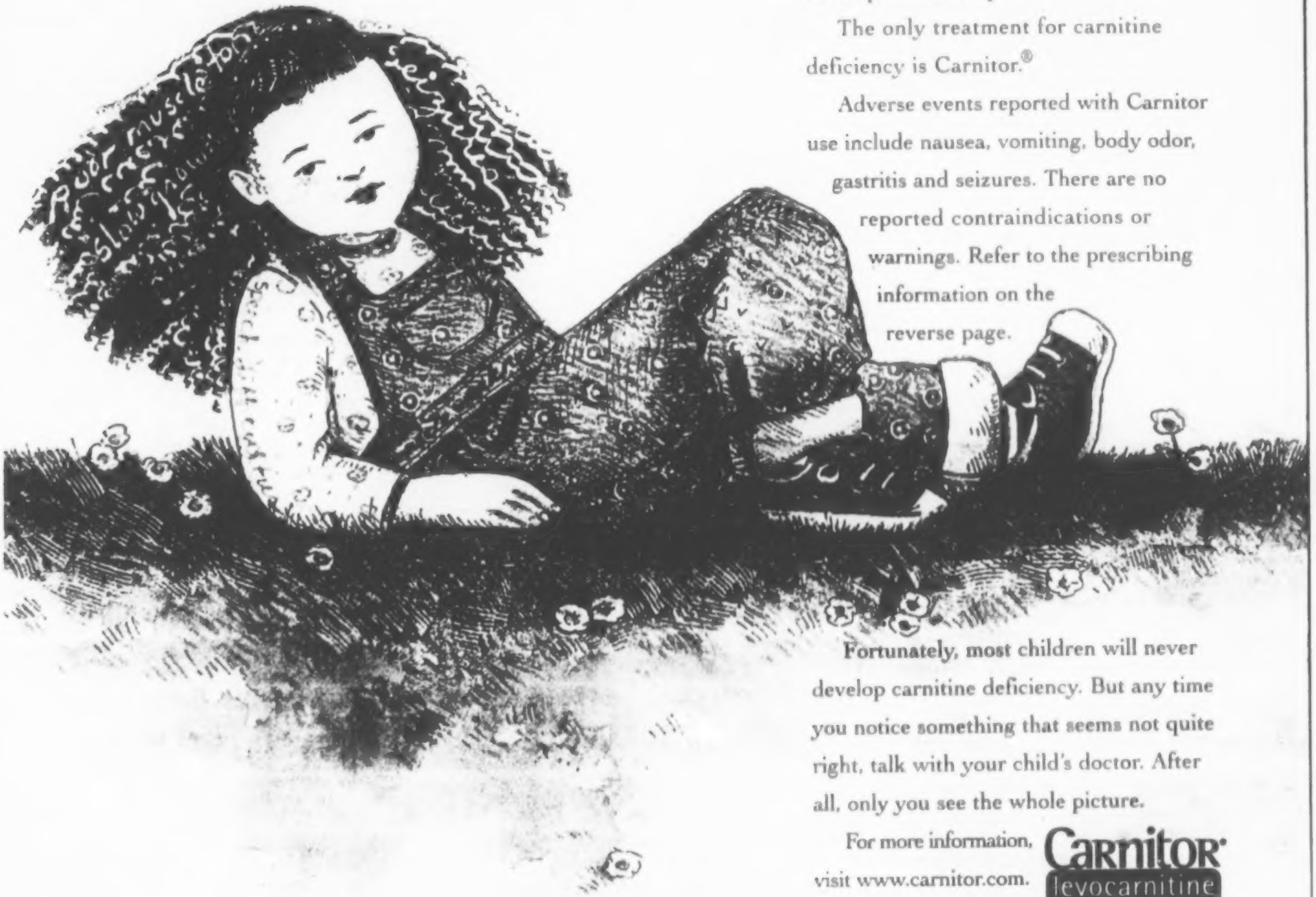
CAN YOU FIND THE SYMPTOMS OF CARNITINE DEFICIENCY IN THIS PICTURE?



No one knows your child as well as you do. So no one's better at seeing the subtle things that affect your child's health. Things like carnitine deficiency.

Carnitine is a naturally occurring substance that's essential in the metabolic process. If the body is deficient in carnitine, the ability of the cells to produce energy and to remove toxic wastes is impaired. And while carnitine deficiency can be serious, its symptoms are hard to detect and are often overlooked.

Signs include muscle weakness, frequent infection, seizures, poor muscle tone, slow growth, speech difficulties, slow weight gain, lack of energy and developmental delay.

The only treatment for carnitine deficiency is Carnitor.®

Adverse events reported with Carnitor use include nausea, vomiting, body odor, gastritis and seizures. There are no reported contraindications or warnings. Refer to the prescribing information on the reverse page.

Fortunately, most children will never develop carnitine deficiency. But any time you notice something that seems not quite right, talk with your child's doctor. After all, only you see the whole picture.

For more information, visit www.carnitor.com. Or call 1-800-447-0169.

Carnitor® levocarnitine
Tablets 330mg • Oral Solution 1g/10mL

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Carnitor®
levocarnitine

Tablets 330mg • Oral Solution 1g/10mL

CARNITOR® (levocarnitine) Tablets (330 mg)
CARNITOR® (levocarnitine) Oral Solution (1 g/10 mL multidose)
FOR ORAL USE ONLY. Not for parenteral use. Rx only.

BRIEF SUMMARY

The following is a brief summary. Please see package insert for full prescribing information.

CLINICAL PHARMACOLOGY

CARNITOR® (levocarnitine) is a naturally occurring substance required in mammalian energy metabolism. It has been shown to facilitate long-chain fatty acid entry into cellular mitochondria, therefore delivering substrate for oxidation and subsequent energy production. Fatty acids are utilized as an energy substrate in all tissues except the brain. In skeletal and cardiac muscle they serve as major fuel. Primary systemic carnitine deficiency is characterized by low plasma, RBC, and/or tissue levels. It has not been possible to determine which symptoms are due to carnitine deficiency and which are due to the underlying organic acidemia, as symptoms of both abnormalities may be expected to improve with carnitine. The literature reports that carnitine can promote the excretion of excess organic or fatty acids in patients with defects in fatty acid metabolism and/or specific organic acidopathies that bioaccumulate acyl CoA esters.

Secondary levocarnitine deficiency can be a consequence of inborn errors of metabolism. CARNITOR® may alleviate the metabolic abnormalities of patients with inborn errors that result in accumulation of toxic organic acids. Conditions for which this effect was demonstrated are: glutaric aciduria II, methyl malonic aciduria, propionic acidemia, and medium chain fatty acyl CoA dehydrogenase deficiency. Autointoxication occurs in these patients due to the accumulations of acyl CoA compounds that disrupt intermediary metabolism. The subsequent hydrolysis of the acyl CoA compound to its free acid results in acidosis that can be life threatening. Levocarnitine clears the acyl CoA compound by formation of acyl carnitine which is quickly excreted.

Levocarnitine deficiency is defined biochemically as abnormally low plasma levels of free carnitine, (less than 20 μmol/L at one week post term) and may be associated with low tissue and/or urine levels. Further, this condition may be associated with a ratio of plasma ester/free levocarnitine levels greater than 0.4 or abnormally elevated levels of esterified levocarnitine in the urine. In premature infants and newborns, secondary deficiency is defined as plasma free levocarnitine levels below age related normal levels.

BIOAVAILABILITY/PHARMACOKINETICS

In a relative bioavailability study in 15 healthy adult male volunteers CARNITOR® Tablets were found to be bio-equivalent to CARNITOR® Oral Solution. Following the administration of 1980 mg b.i.d., the maximum plasma concentration level (C_{max}) was 80 nmol/mL and the time to maximum concentration (T_{max}) occurred at 3.3 hours. There were no significant differences for AUC and urinary excretion observed between these two formulations.

In the same bioavailability study of 15 healthy adult males, CARNITOR® (levocarnitine) Injection administered as a slow 3 minute bolus intravenous injection at a dose of 20 mg/kg showed that free levocarnitine plasma profiles are best fit by a two compartment model. Approximately 76% of free levocarnitine is eliminated in the urine. Using plasma levels uncorrected for endogenous levocarnitine, the mean distribution half life was 0.585 hours and the mean apparent terminal elimination half life was 17.4 hours following a single intravenous dose.

The absolute bioavailability of L-carnitine from CARNITOR® Tablets and Oral Solution was determined compared to the bioavailability of L-carnitine from CARNITOR® Injection Intravenous in 15 healthy male volunteers. After correction for circulating endogenous levels of L-carnitine in the plasma, absolute bioavailability was 15.1% ± 5.3% for L-carnitine from CARNITOR® Tablets and 15.9% ± 4.9% from the Oral Solution.

Total body clearance of L-carnitine (Dose/AUC including endogenous baseline levels) was a mean of 4.00 L/hr. Endogenous baseline levels were not subtracted since total body clearance of L-carnitine does not distinguish between exogenous sources of L-carnitine and endogenously synthesized L-carnitine. Volume of distribution of the intravenously administered dose above baseline endogenous levels was calculated to be a mean of 29.0 L ± 7.1 L (approximately 0.39 L/kg) which is an underestimate of the true volume of distribution since plasma L-carnitine is known to equilibrate slowly with, for instance, muscle L-carnitine.

L-carnitine was not bound to plasma protein or albumin when tested at any concentration or with any species including the human.

INDICATIONS AND USAGE

CARNITOR® (levocarnitine) is indicated in the treatment of primary systemic carnitine deficiency. In the reported cases, the clinical presentation consisted of recurrent episodes of Reye-like encephalopathy, hypoketotic hypoglycemia, and/or cardiomyopathy. Associated symptoms included hypotonia, muscle weakness and failure to thrive. A diagnosis of primary carnitine deficiency requires that serum, red cell and/or tissue carnitine levels be low and that the patient does not have a primary defect in fatty acid or organic acid oxidation (see Clinical Pharmacology). In some patients, particularly those presenting with cardiomyopathy, carnitine supplementation rapidly alleviated signs and symptoms. Treatment should include, in addition to carnitine, supportive and other therapy as indicated by the condition of the patient.

CARNITOR® (levocarnitine) is also indicated for acute and chronic treatment of patients with an inborn error of metabolism that results in a secondary carnitine deficiency.

CONTRAINDICATIONS

None known.

WARNINGS

None.

PRECAUTIONS

General

CARNITOR® (levocarnitine) Oral Solution is for oral/internal use only.

Not for parenteral use.

Gastrointestinal reactions may result from too rapid consumption of carnitine. CARNITOR® (levocarnitine) Oral Solution may be consumed alone, or dissolved in drinks or other liquid foods to reduce taste fatigue. It should be consumed slowly and doses should be spaced evenly throughout the day to maximize tolerance.

Carcinogenesis, mutagenesis, impairment of fertility

Mutagenicity tests performed in *Salmonella typhimurium*, *Saccharomyces cerevisiae*, and *Schizosaccharomyces pombe* indicate that CARNITOR® (levocarnitine) is not mutagenic. Long-term animal studies have not been conducted to evaluate the carcinogenicity of the compound.

PREGNANCY

Pregnancy Category B.

Reproductive studies have been performed in rats and rabbits at doses up to 3.8 times the human dose on the basis of surface area and have revealed no evidence of impaired fertility or harm to the fetus due to CARNITOR®. There are, however, no adequate and well controlled studies in pregnant women. Because animal reproduction studies are not always predictive of human response, this drug should be used during pregnancy only if clearly needed.

NURSING MOTHERS

It is not known whether this drug is excreted in human milk. Because many drugs are excreted in human milk, a decision should be made whether to discontinue nursing or to discontinue the drug, taking into account the importance of the drug to the mother.

PEDIATRIC USE

See Dosage and Administration.

ADVERSE REACTIONS

Various mild gastrointestinal complaints have been reported during the long-term administration of oral L- or D,L-carnitine; these include transient nausea and vomiting, abdominal cramps, and diarrhea. Mild myasthenia has been described only in uremic patients receiving D,L-carnitine. Gastrointestinal adverse reactions with CARNITOR® (levocarnitine) Oral Solution dissolved in liquids might be avoided by a slow consumption of the solution or by a greater dilution. Decreasing the dosage often diminishes or eliminates drug-related patient body odor or gastrointestinal symptoms when present. Tolerance should be monitored very closely during the first week of administration, and after any dosage increases.

Seizures have been reported to occur in patients with or without pre-existing seizure activity receiving either oral or intravenous levocarnitine. In patients with pre-existing seizure activity, an increase in seizure frequency and/or severity has been reported.

OVERDOSAGE

There have been no reports of toxicity from carnitine overdosage. The oral LD_{50} of levocarnitine in mice is 19.2 g/kg. Carnitine may cause diarrhea. Overdosage should be treated with supportive care.

DOSAGE AND ADMINISTRATION

CARNITOR® (levocarnitine) Tablets.

Adults: The recommended oral dosage for adults is 990 mg two or three times a day using the 330 mg tablets, depending on clinical response.

Infants and children: The recommended oral dosage for infants and children is between 50 and 100 mg/kg/day in divided doses, with a maximum of 3 g/day. Dosage should begin at 50 mg/kg/day. The exact dosage will depend on clinical response.

Monitoring should include periodic blood chemistries, vital signs, plasma carnitine concentrations and overall clinical condition.

CARNITOR® (levocarnitine) Oral Solution.
For oral use only. **Not for parenteral use.**

Adults: The recommended dosage of levocarnitine is 1 to 3 g/day for a 50 kg subject, which is equivalent to 10 to 30 mL/day of CARNITOR® (levocarnitine) Oral Solution. Higher doses should be administered only with caution and only where clinical and biochemical considerations make it seem likely that higher doses will be of benefit. Dosage should start at 1 g/day, (10 mL/day), and be increased slowly while assessing tolerance and therapeutic response. Monitoring should include periodic blood chemistries, vital signs, plasma carnitine concentrations, and overall clinical condition.

Infants and children: The recommended dosage of levocarnitine is 50 to 100 mg/kg/day which is equivalent to 0.5 mL/kg/day CARNITOR® (levocarnitine) Oral Solution. Higher doses should be administered only with caution and only where clinical and biochemical considerations make it seem likely that higher doses will be of benefit. Dosage should start at 50 mg/kg/day, and be increased slowly to a maximum of 3 g/day (30 mL/day) while assessing tolerance and therapeutic response. Monitoring should include periodic blood chemistries, vital signs, plasma carnitine concentrations, and overall clinical condition.

CARNITOR® (levocarnitine) Oral Solution may be consumed alone or dissolved in drink or other liquid food. Doses should be spaced evenly throughout the day (every three or four hours) preferably during or following meals and should be consumed slowly in order to maximize tolerance.

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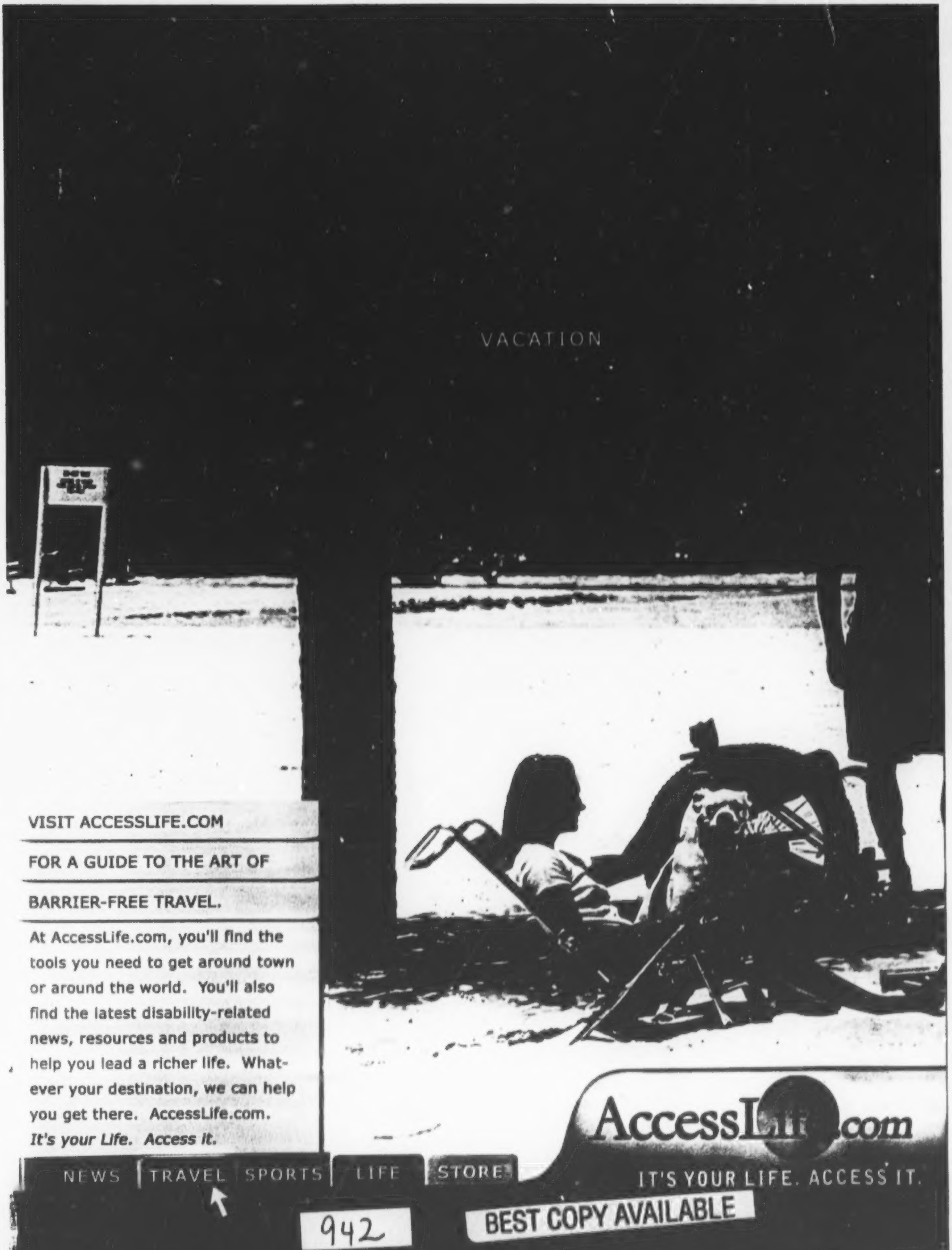
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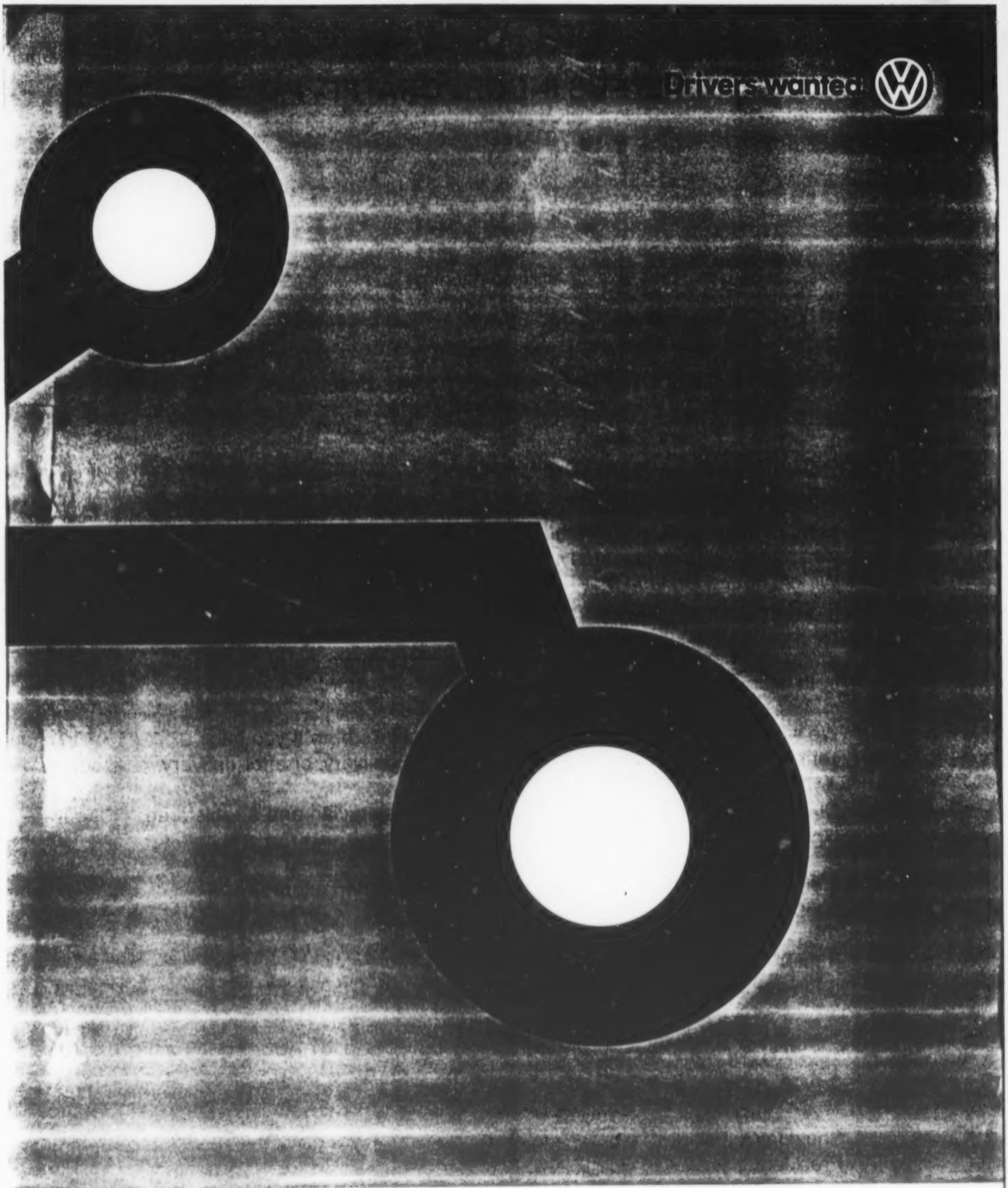
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Dear Parents:

When my son was born with cerebral palsy, my family and I had no idea how our lives would be affected. We did not see how vulnerable our child was and how he would need our care and protection for the rest of his life. We did not understand that we would become his life-line in so many ways, and he in turn would consume our lives.

As an attorney, I have become deeply involved in brain injury and other birth injury cases throughout the country.

We would be interested in looking into your child's birth if you had complications either during pregnancy, during delivery, or after delivery.

Our medical staff includes a board certified obstetrician and a registered obstetrical nurse.

Please call 1-800-888-LAWS and speak with either an attorney or a registered nurse.

Remember, there are time restrictions.

Sincerely,

Sheldon O Zisook

Sheldon O. Zisook
President

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Cover: Louis Muller, a student at Melmark, Inc., in Pennsylvania, and his teacher Rebecca Grossman are absorbed in a school project.

THANKS TO MELMARK, INC., FOR THIS PHOTO

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- *To reach out to mothers and fathers of children and young adults who have disabilities and special healthcare needs.*
- *To empower parents and professionals by providing practical information and emotional support.*
- *To appreciate that parents are the most important experts in the lives of their children.*
- *To energize parents and professionals.*
- *To share ideas and experiences so parents, professionals, people who have disabilities, and other advocates can learn from one another and better collaborate to serve all children and families.*

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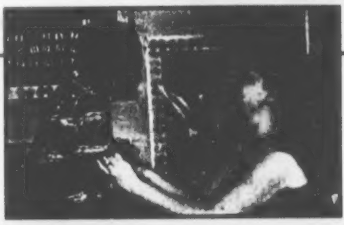

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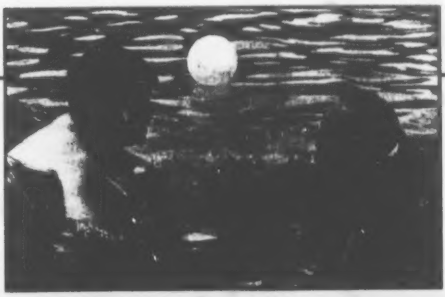

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MEMORIAL TO

Maxwell J. Schleifer, PhD

1927-2000

Max Schleifer—professor, clinician, researcher, scholar, and advocate—founded Exceptional Parent magazine as a means of providing practical advice, counsel, and connections for anguished and overwhelmed parents of children with disabilities. Max died suddenly on July 24. He left behind a legacy of 30 years of published wisdom, humor, caring and courage, and a commitment to much more beyond that.

There was no professional Max, no personal Max, no off-hour Max, no on-vacation Max, no deadline Max, no esoteric Max. There was only Max, always the same, all the time. If you knew Max for a day, you knew him for a lifetime. He was a man of intense study and concentration, and a wide grin that started in his eyes, spread across his face, and usually ended in a husky laugh. He was a man of great intellect and voracious reading, and a driving commitment to sports and camping. He was a man of strong opinions and gentle compromises. He was a man of great practical compassion.

Max believed in people—all people. He found them fascinating and committed himself to helping them and understanding them, not just in his chosen professional field but in his neighborhood, his community, his beloved Boston, his classrooms, his offices, his state, his country, his world. And not as a guru aloof from the fray, isolated in a world of vague theory or goopy sentimentality. Max believed in looking square at and deep into life and lives and asking, "What is so? Why is it so? Why do we think it is so? What are we missing? What do we do about it?"

Max was a creator. He founded a camp for children with psychological disabilities. He founded a hospital program so that parents of children requiring hospital stays and procedures could stay with them. He founded a magazine for parents of children with all types of disabilities.

Max was also an inspiration. It was not the great things he did—though he did so many. It was not the profound things he said—though he distilled truths and could chart straight paths with great clarity. It was Max as Max. As he made his way through life, he pulled you with him, trusting, learning, laughing, worrying, studying, writing, editing. And he made you feel so sure of yourself.

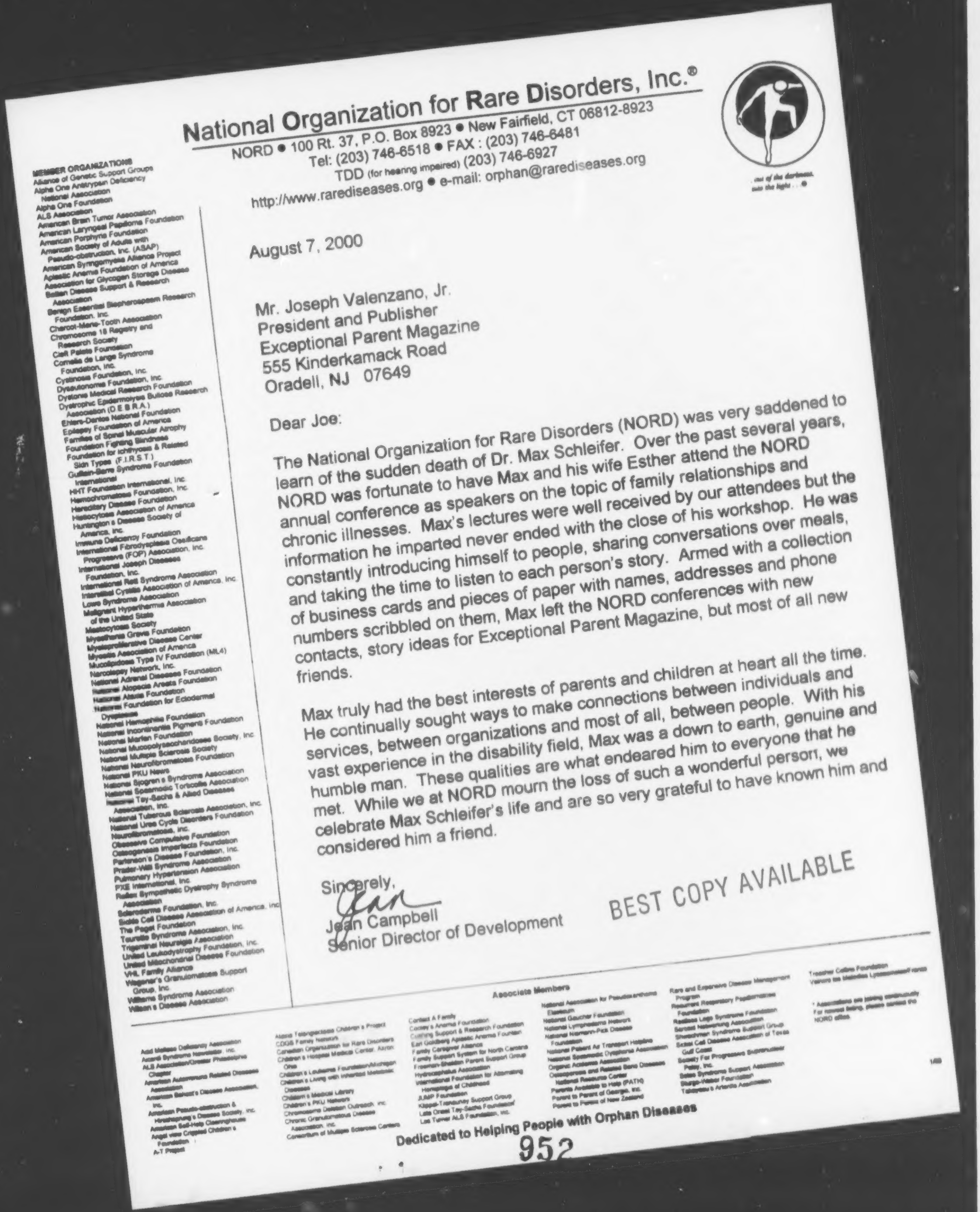
Those of us who worked with Max Schleifer will always be privileged to know and say that we learned directly from the visionary himself, the "founding father" of Exceptional Parent magazine. We will proudly wear the EP initials next to our names, like a badge in honor of this learned, yet playful man. We will always have a solid role model living in our hearts to guide us. When speaking with him, it was always clear that Exceptional Parent was Max in ink and paper; reading the magazine showed us Max personified.

Everything good that needs to be said about Max has already been said in hundreds of issues of Exceptional Parent magazine and through the thousands of lives he touched and continues to touch. Max's family and friends should feel joyful to know that Max was raring to do work for his priceless fifth child, Exceptional Parent, up to his last hour, and that his magazine's impact on the lives of exceptional parents and children will always be with us.

Max Schleifer was an editor-in-chief, a teacher, a psychologist, a husband, a father, a grandfather, and a wonderful friend. He was and still is the symbol of what EP stands for: Excellence, Passion and Kindness. He was an exceptional man who knew where priorities should lie. We will miss him. And we will honor him by continuing his legacy of practical compassion for parents of children with disabilities in the magazine he founded 30 years ago this year.

Thank you, Max, for giving the world so much of yourself.

—The Exceptional Parent Staff



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August 7, 2000

Mr. Joseph Valenzano, Jr.
President and Publisher
Exceptional Parent Magazine
555 Kinderkamack Road
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Dear Joe:

The National Organization for Rare Disorders (NORD) was very saddened to learn of the sudden death of Dr. Max Schleifer. Over the past several years, NORD was fortunate to have Max and his wife Esther attend the NORD annual conference as speakers on the topic of family relationships and chronic illnesses. Max's lectures were well received by our attendees but the information he imparted never ended with the close of his workshop. He was constantly introducing himself to people, sharing conversations over meals, and taking the time to listen to each person's story. Armed with a collection of business cards and pieces of paper with names, addresses and phone numbers scribbled on them, Max left the NORD conferences with new contacts, story ideas for Exceptional Parent Magazine, but most of all new friends.

Max truly had the best interests of parents and children at heart all the time. He continually sought ways to make connections between individuals and services, between organizations and most of all, between people. With his vast experience in the disability field, Max was a down to earth, genuine and humble man. These qualities are what endeared him to everyone that he met. While we at NORD mourn the loss of such a wonderful person, we celebrate Max Schleifer's life and are so very grateful to have known him and considered him a friend.

Sincerely,
Jean
Jean Campbell
Senior Director of Development

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An Exceptional Man,

On Tuesday morning, July 25, while driving to Baltimore for business, my car phone rang. On the other end was the familiar voice of Esther Schleifer, wife of Max Schleifer, Editor-in-Chief of Exceptional Parent. The tone in Esther's voice had a different sound to it that morning. When she asked me to pull over to the side of the road, I knew something was wrong. On the shoulder of the New Jersey Turnpike, with rush-hour traffic whizzing past, Esther told me sadly and simply, "Max died."

Those words cut through me like a knife. "Max died."

Max was more than a colleague. He was someone I had developed a close relationship with. He was a friend. We had talked endlessly—in our office, in my home and his—of our families, sports, politics, religion, economics, and a host of other things funny, sad, important, challenging, light-hearted, business, personal, formidable, inconsequential, timely, sentimental, light, or compelling. We talked, and sometimes we argued, but, always, we had a mutual trust and respect for one another that transcended the walls that tend to exist between publisher and editor. And that mutual trust and respect is what made us better at what we did—and do.

Max was an advisor, a father, a teacher, an innovator and a person who genuinely loved life and people. And now, in an instant, he is gone. "Max died."

I collected my thoughts that day and then began the painful task of letting our staff know, canceling appointments for the next day, and arranging to make the trip north to attend the funeral services in Newton, MA. I was not alone. Except for the skeleton staff that remained, our entire company made the four-and-a-half-hour journey to attend the services. Even my mother made the trip with us. She had come to know Max and wanted to express her condolences to Esther and her family. I was not surprised at this. Max and his wife Esther—they were inseparable. And they were loved and respected by all of us. We had to be there.

I listened attentively to the Rabbi tell us about Max's life and his accomplishments. His children then spoke lovingly of their father, remembering family stories that made us smile and even laugh. His friend of 40 years, David Brous, then painted a picture of Max that so eloquently described the man. He said that Max was not only a brilliant teacher, professor, scholar, and writer, but was as comfortable in the kitchen arguing over politics, sports or his beloved Boston as he was in the boardroom talking about growth strategies and ways to reach out and help families and children.

Always the children. Children, for Max, were the real treasure we have as individuals, as a nation, as a world. That philosophy was what endeared him to so many, because it was genuine, the real deal.

"Max died." All too often we tend to dwell on death and the sorrow it brings. It is understandable and a natural human emotion. I prefer to focus not on how Max died, but on how he lived. Simply stated, our lives were enriched because Max Schleifer walked among us. Max Schleifer founded Exceptional Parent 30 years ago. His vision created a vehicle for families of children with disabilities and special healthcare needs to reach out to one another, to share

Max and his wife Esther.

The following are tributes from some of Max's dearest friends and colleagues:

"I think that Max is someone who always looked to raise someone's potential or increasing a person's realization of their potential. I never heard him talk down to someone, but I did see him challenge people to be better than they thought they could be. 23 years ago when I came to Boston as a graduate student, Max and Esther and their family opened up their home, and I think that generosity is another part of who Max was."

—Rabbi Jonathan Biatch

"In the 40 years I knew Max, I watched him progress in his professional career as a teacher, child advocate, psychologist, editor, and counselor.

"His work brought him many satisfactions. Over the last 30 years, he often remarked that among the greatest rewards his work brought was his contact with the parents he met through the pages of the magazine he founded, Exceptional Parent.

"Max was a pioneer leader in the world of new ideas and programs for children with disabilities. He appreciated that his magazine afforded him the opportunity to dialogue with parents about their everyday needs, hopes, fears, and aspirations. He was particularly pleased that the advertisements opened a world to show parents where they could get products and services to help their children. He used "letters to the editor" as a vehicle for parents to communicate with other parents as well as professionals.

"Max, the loving father of four of his own children, also understood that every parent had the same dreams and prayers for every child's future that he did. He was an exceptional parent himself."

—David Brous

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an Exceptional Legacy

experiences and to let each other know that they are not alone, and to care. EXCEPTIONAL PARENT for Max was, and is, a way for parents to bond together; to provide practical advice and emotional support; and to help families interact better with physicians, allied healthcare professionals, and teachers so that their children will have the very best opportunity to contribute and be a part of this great nation and society. And remember, all of this was many years before the ADA was even a dream.

I believe that, in the final analysis, each of us would like to leave this world believing that our lives meant something; that we made a difference. Max left us far too soon, but with a legacy of caring, compassion, and courage. He left us better for having touched our lives; his teachings and his creations will endure in our minds and in our hearts.

I never knew Max to put on airs or try to be someone he was not. What he was was intellectually brilliant, a Harvard University undergraduate with a PhD in clinical psychology from Boston University. He was a college professor who worked with juvenile delinquents. He wrote books. He coached baseball. He lectured in the classroom and he was an accomplished athlete. His stories made us laugh but at the same time taught us valuable lessons of life. For at the very core of Max was the teacher. He loved sharing his experiences and his knowledge, and we are stronger and better for his efforts. Every hour he spent with our staff in New Jersey made us better at what we do. And after each lesson, we were reminded of what it is we do and why we exist to help families and professionals in the development of children and adults with disabilities and special healthcare needs. Max may not be with us physically, but his lessons and his philosophy fortified the foundation of EXCEPTIONAL PARENT and will help us stay the course in this new millennium.

So, who will replace Max? A natural human question. Replace Max? No one will replace Max. Someone will take his position as Editor-in-Chief, but no one could take his place.

Husband, father, professor, psychologist, philosopher, writer, speaker, coach, athlete, confidant: those are all accurate descriptions of the man. But the two descriptions that mean the most to me and how I will remember Max Schleifer are as friend and teacher. I miss my friend Max, and my world is a little empty without him. But, I will remember what he taught me—what he taught all of us at EXCEPTIONAL PARENT—and that memory will live on in the work we do.

The greatest tribute all of us can pay to Max is to continue the legacy he left of caring, compassion and sensitivity. And I assure you, that is precisely what we will do with the publication he founded 30 years ago this year and nursed as Editor-in-Chief for those 30 years.

Joseph M Valenzano

Joseph M. Valenzano, Jr.
President, CEO & Publisher, EXCEPTIONAL PARENT, August 2000

"Max was a creator, a teacher, and a friend to me. Many years ago, when I was the managing editor of Exceptional Parent, I had the great pleasure of getting to work with, and more important, begin a long-lasting friendship with Max and his dear wife Esther. I remember being so touched by the love they shared for one another. Esther almost always accompanied Max on his trips to the EP office and his journeys across country to attend meetings and conferences. Esther often reminded me that their strong relationship was based on communication.

"Max was great at communicating. He had the best stories to tell about his days in his practice working with families. He started this magazine 30 years ago because he saw that families caring for kids with disabilities needed additional resources. He often used those stories to illustrate the different needs that parents and kids have. He also really enjoyed linking people to the appropriate resources. Max and Esther would frequently listen to issues I was going through raising Brielle, my six-year-old daughter with mitochondrial myopathy. They were always able to point me in the right direction to get my questions answered, and quite often we used these experiences as feature ideas in the magazine.

"It was exciting planning out the future issues of EP with Max. As the creator of this exceptional resource, he liked to keep to the basics. The editorial staff was always asked, "How will this article benefit parents?" He taught us ways to make our features practical but informational, and to always think about linking parents to additional resources.

"Last year, when I decided to apply for a position as a Joseph P. Kennedy Jr. Public Policy Fellow in Washington D.C., he offered his unconditional support by writing letters of reference, and helping me prepare for the interview process. When I was later chosen, Max was one of the first people I called to share the good news. We had a lot of fun reminiscing about his own experiences living in D.C. while on sabbatical. In true Max fashion he made sure I had a list of all his D.C. contacts, and that I had a pass to the Smithsonian in my back pocket.

"I am grateful to have known Max. He helped me to become a better parent, advocate, student, and friend."

—Julie Venners Hacker

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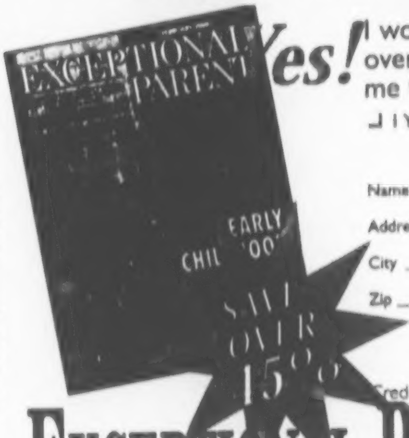

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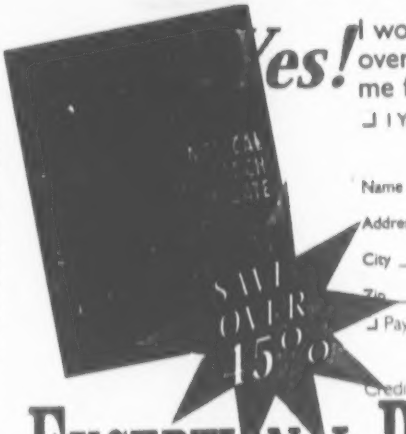

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Exceptional Parent

is the magazine for parents and professionals involved in the care and development of children and young adults with special needs, including Physical Disabilities, Developmental Disabilities, Mental Retardation, Autism, Epilepsy, Learning Disabilities, Perceptual Disabilities, Hearing Impairments, Vision Impairments, Emotional Problems, Chronic Illness.

Exceptional Parent's MISSION IS TO:

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Search & Respond

About Search & Respond

Search and Respond is an opportunity for our readers to exchange information about their practical experiences in meeting the everyday challenges of life with a child or adolescent who has a disability. In this column, "S" represents Search letters and "R" represents Respond letters received to a previously printed Search. "Instant S&R" is a new feature which represents e-correspondence we have downloaded from our Web site. All Responds are forwarded to the writers of the original Searches; some are published. Published letters may be edited for purposes of space and clarity. We also expect parents to consult appropriate professionals.

When sending correspondence, please indicate whether it is a Search or a Respond. For Responds, be sure to note in which issue the original Search letter appeared. Please remember to include a phone number on all correspondence, in the event that more information is required. Write to: Exceptional Parent, Attn: Search/Respond, 555 Kinderkamack Rd., Oradell, NJ 07649-1517; Fax to: (201) 634-6570; E-mail to epedit@aol.com; or visit Search and Respond on our Web Site: http://www.eparent.com.

For information about specific disabilities, contact: the National Organization for Rare Disorders (NORD), 100 Rt. 37, PO Box 8923, New Fairfield, CT 06812; (800) 999-6673; (203) 746-6518; Web site: http://www.rarediseases.org. Also, see the "National Resources for Specific Disabilities" directory in Exceptional Parent's 2000 Resource Guide (January 2000, starting on page 30).

Each month, Chris Feudtner, MD, PhD, reviews Search & Respond for accuracy and completeness. Dr. Feudtner is a pediatrician at the Pediatric Care Center of the University of Washington in Seattle, and is currently a Robert Wood Johnson Clinical Scholar. Look for Dr. Feudtner's comments on certain Search & Respond letters.

S Group home

Six years ago, my husband and I adopted our granddaughter, who is 11-years-old and has cerebral palsy, autism.cortical blindness, mental retardation, and is developmentally delayed. She cannot walk, has limited speech, and can be combative.

We adopted her to keep her out of an institution. My husband passed away four years ago, and I have been slowly losing the battle (financially, physically, and emotionally) to keep her. I am getting too old and physically impaired to care for her without help. Because it was a "family adoption" and because of my income, I cannot get any financial help. I could place her in a foster home (if one ever becomes available) or in a rest home.

My wish would be to keep her with me. She has bonded with me, and knows how to love. The only option I would agree to is to place her in a group home where there are children her own age. I live in Oregon, and know of no group homes for children under age 18. I need to know what states have homes and the criteria for placement.

Unfortunately, I have no choice. I had hoped to keep her with me until she was 18, then place her in a group home, but I have run out of options.

ST, Oregon

EDITOR'S NOTE:
Contact the Family Voices representative for your state. In Oregon, the contact is Lauren Bridge; phone number: (503) 215-2504; E-mail: LBridge@providence.org. The phone number for the national office is (888) 835-5669; E-mail: kidshealth@familyvoices.org.

S Answering questions

My daughter is 3-years-old and has cerebral palsy—mild spastic diplegia that mainly affects her gait, although she also has some trouble with fine motor tasks. She will be attending nursery school this year, and the teachers have asked me to provide them with responses to innocent questions from the other children such as, "Why does she walk like that?" and "Why does she have those things (ankle/foot orthotic devices, or AFOs) on her legs?" I want to give responses that are simple, matter of fact, and highlight the fact that she is just another great kid like them. Does anyone have any specific ideas?

Heather, via the EP Web site

Dr. Feudtner: How about, "Oh, she was born with special muscles that are a little bit too strong."

S Undiagnosed

My son is 2-years-old and is a strong, patient, and happy child, who brings joy to me and all around him. He has involuntary muscle movements 24 hours a day, which makes it hard for him to sleep properly. Developmentally and cognitively, he is at the level of a 2-month-old. He is also nonverbal and has cortical blindness. Last May, he had a fundoplication (surgical reduction of the opening between the stomach and the esophagus to treat gastric reflux) and pyloroplasty (surgery to enlarge the opening between the stomach and the duodenum). After his surgery, he began having infantile spasms. He has been on countless anticonvulsant medications. They have all failed, as has the ketogenic diet. I also noticed a profound change in my son. His normal crying and laughing responses had diminished. An MRI revealed that he was losing brain-cell tissue and his brain was shrinking. There was no explanation of how or why this was happening. Every doctor we have been to has been unable to give us a diagnosis. His last EEG showed that he was having about 100 seizures per day. He receives therapies at home. I am already in contact with MUMS (Mothers United for Moral Support). I am hoping they will be able to find another child like my son and we can get through this together. I would welcome hearing from anyone who has a child with symptoms similar to my son's.

CL, via the EP Web site

S Potty training

My son is 8-years-old and has Down syndrome. We have tried many different methods of potty training, with no results. He goes through all the motions (pulling down his pants, sitting down, and flushing) with total compliance and willingness, but he does not actually "go." He will hold in his urine from 7 AM until late at night. We think that his withholding has more to do with habit, perhaps in response to too much pressure last year from the staff at his school (they made it a focal point of his school days for many

continued on page 22

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DYNAVOX

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Search & Respond

continued from page 20

months). He gets great pleasure from rituals and we are wondering if not "going" is part of the pattern. We think he is ready and willing to use the potty, but is unable to break the pattern. We would like to know if anyone else has had this problem.

LM, via the EP Web site

Respond

Sensory integration dysfunction

KH (July 2000) has a 2-year-old son who seems bright, but is non-verbal, and has behavior problems. KH wanted to know if other parents had experienced behavior problems in children this young.

My grandson displays many of the same symptoms as your son. He also did not speak, and as a result of being frustrated, did all the hitting, hair pulling, etc., that your son displays. It turns out he has something called sensory integration dysfunction. He is being treated with occupational and speech therapies.

Barbara, via the EP Web site

Sleep difficulties

Tom (July 2000) has a 4-year-old son with cerebral palsy, microcephaly, asthma, and gastroesophageal reflux. His son has difficulty falling asleep, and will awaken with a scream after five minutes of sleeping, until he falls into a deep sleep.

I have a few suggestions that may improve your son's sleep. Some may sound a bit far-fetched, but they may be worth looking into.

1. Speak to an allergist or nutritionist who has experience with children with special needs. Your son may be sensitive or allergic to a particular food (it may also be a factor in his reflux).
2. Try swaddling him in a soft blanket. This may give him a sense of security and will stop sudden involuntary movements that may startle and awaken him.
3. Try a soothing bath using calming herbs (chamomile and lavender).
4. Try a vibrating pillow or mat. It can make children more excited, or calm them, so you might want to try it during the day and see its effect on your son.

HV, via the EP Web site

My daughter finally had to have fundoplication surgery to fix her terrible time with GERD (gastroesophageal reflux disease). She awoke constantly due to the pain of "silent reflux." Her sleeping improved a great deal after the surgery. However, she remains on medication due to severe delay in gastric emptying and the resulting painful gas and chronic constipation. At that time, she still woke up frequently in pain from the gas. We tried several drugs for gas and many different laxatives (OTC and prescribed), but nothing gave her relief. Last month, a gastroenterologist put her on Miralax®, a saline laxative that is used to help people eliminate again after surgery. It is tasteless and is mixed as crystals into apple juice. It can be used long-term with no bad effects. It has kept my daughter regular, and has greatly reduced gas and gas pain. She is sleeping even better now.

CN, via the EP Web site

> EDITOR'S NOTE:
> *You might consider asking your child's physician for a referral to a pediatric sleep clinic.*

Pediatric dentist

GJ (May 2000) has a 20-year-old son with mental retardation who has a dental cavity. The dentist suggested using general anesthesia to fill the cavity, even though GJ's son takes seizure medication. GJ is looking for information on how to proceed.

Last year, my 11-year-old son, who is developmentally delayed, needed extensive dental work including several cavities filled and some teeth extracted. Our original plan was to have everything taken care of at once under anesthesia.

We ended up working with our regular dentist, who filled his cavities with no anesthesia. The dentist explained everything he was going to do beforehand, and showed him the drill and how it worked. He also said that all my son had to do was raise his hand, and the dentist would stop drilling.

We used an oral surgeon for the tooth extractions. He contacted my son's doctor to check for any special care that needed to be taken and followed his recommendations. The oral surgeon also had the nurse put an anesthetic cream on my son's arm so he did not even feel the needle. During the procedure, my son was monitored constantly. It sounds like your son has seen a dentist regularly and has been cooperative. The last thing you want is for him to start fearing dental visits.

DC, via the EP Web site

Instant S&R

Hands in diapers

My 3-year-old grandson with sensory integration dysfunction has a terrible habit of digging into his dirty diaper and either smearing and/or eating the feces. He does not seem to be turned off by the taste or smell. If anyone has any solutions, I would greatly appreciate hearing what was done, or can be done to stop this behavior.

Barbara, via the EP Web site

My son is 6-years-old and remains in a diaper. He has gone through phases where he would reach into his dirty diaper and grab his feces. We found that altering his dress helped to control this. Using the equivalent of an infant onezie kept him from getting his hands into his pants. We shopped until we found stores that sold shirts with snaps on the bottom in larger sizes. Fabric stores sell strips of snaps, and a shirt could be altered to have snaps at the bottom. We found that if he could not get at his diaper, he would eventually stop trying.

Bridget, via the EP Web site

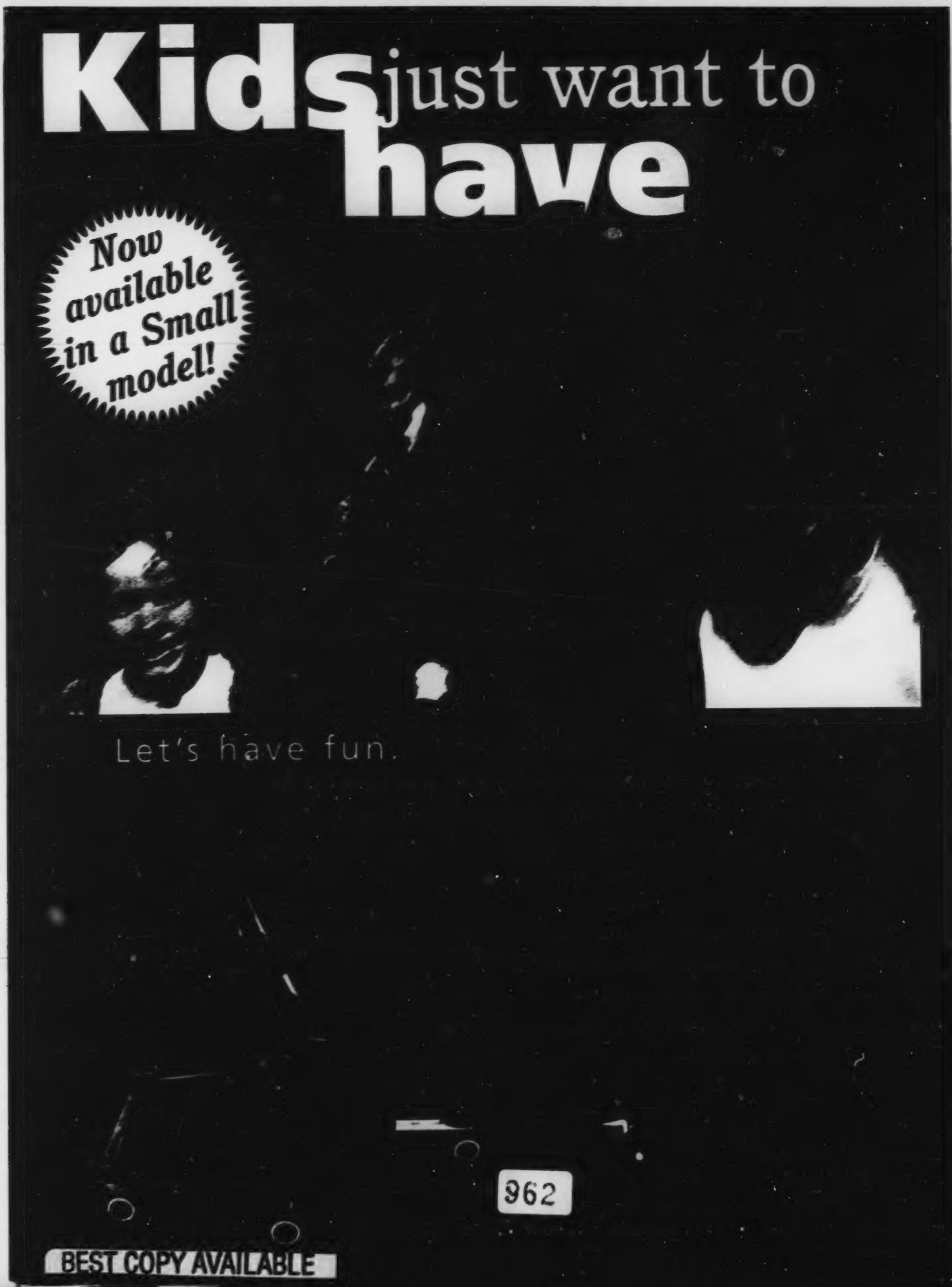
Need a double buggy

We are desperately trying to find a double buggy for our 7-year-old daughter who has cerebral palsy, and our 6-month-old son who has no disability.

SB, via the EP Web site

I have a triple stroller that is not specifically for children with special needs, but it has worked well with my daughter who has cerebral palsy and needs a lot of support. It is called a Runabout Stroller, and it comes as a single, double, triple, or four passenger. Their phone number is (800) 832-2376.

Polly, via the EP Web site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Newborn Screening Awareness Month

September has been declared Newborn Screening Awareness month in a collaborative effort among numerous parents groups, including the Tyler for Life Foundation.

Newborn screening lapel pins are being sold to be worn everyday in September as a symbol of support for newborn screening. The groups involved in this initiative are hoping to sell at least 20,000 pins by September 30. To purchase pins contact the Tyler for Life Foundation at Web site: http://www.tylerforlife.com or E-mail: tiffany.young@unisys.com/.

Free

"Life After SCI"

Video

Altimate Medical Inc. is distributing a new video called "Life After SCI: Vol. 1," which has information on various subjects that will encourage and motivate newly injured individuals with spinal cord injury (SCI). Subjects include: boarding planes, renting cars, downhill 4-wheeling, hand cycling, wheelchair softball, motivational interviews, importance of standing, and going to school.

The video is hosted by Mark Schmitt, who suffered a T-12 SCI himself. According to Schmitt, "This video will help others to deal with this change in life and inspire them to try new adventures." Although the video deals with SCI, it is helpful for any individual who uses a wheelchair. This video is the first release in a series of "Life After SCI" videos. "Life After SCI: Vol. 2" is scheduled for release in December 2000. To request a free video, call Altimate Medical Inc., at (800) 342-8968.

CALENDAR OF EVENTS

10/3-5 **Medtrade**

ORANGE COUNTY CONVENTION CENTER, ORLANDO, FL

This conference, primarily for home healthcare professionals, offers 200 educational seminars and workshops, over 250,000 healthcare products and services, and the chance to meet and exchange ideas with other home healthcare professionals. For more information call (877) 835-7232; Web site: http://www.medtrade.com.

10/13-15 **National Organization for Rare Disorders (NORD) "A Gateway to Hope"**

RENNAISANCE ST. LOUIS HOTEL, ST. LOUIS, MO

The patient/family track will include workshops on genetic counseling, financial planning, and undiagnosed diseases. The second track, for support groups, will include workshops on conference planning and legal issues. For more information contact Dolores Sugasa at NORD: (203) 746-6518 x210, or E-mail: dsugasa@rarediseases.org.

10/20 **4th Annual Great Beginnings Conference**

SHERATON FRAMINGHAM, FRAMINGHAM, MA

This conference is sponsored by the Center for the Development of Human Services and the University of Massachusetts Amherst Department of Communications Disorders. The event is dedicated to the advancement of experiences of early childhood and allied pediatric health professionals. For more information contact Human Services Management Corp. at Phone: (508) 478-2631 x117.

10/20-22 **Abilities Expo**

BAYSIDE EXPOSITION CENTER, BOSTON, MA

Attendees will learn about the latest in assistive living products and services, as well as answers to important questions concerning insurance coverage, government regulations, and available services. For information call (800) 382-3085; Web site: http://www.abilitiesexpo.com.

10/21 **National Association for Down Syndrome (NADS)**

"Celebrating 40 Years of Progress"

RAMADA CONGRESS HOTEL, CHICAGO, IL

Topics will include obtaining proper early intervention, creative play to enhance development, and how to create and maintain positive parent-professional relationships in the school environment. For more information call NADS at (630) 325-9112; Web site: http://www.nads.org.

10/28-11/1 **2000 American Academy of Pediatrics Annual Meeting**

CHICAGO HILTON & TOWERS, CHICAGO, IL

This conference will feature topics such as legislation and advocacy, adolescent health, community pediatrics, and many more topics related to pediatric healthcare. For more information contact the AAP at (847) 434-4000 or visit their Web site at http://www.apa.org.

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In fact, MetDESK recently received the *National Business & Disability Council's Valued Customer Gold Award of Honor* in recognition of MetLife's leadership in responding to the special needs of families of children with disabilities.

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Circle #73

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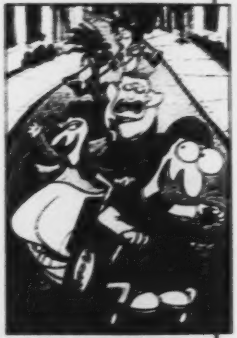
Parent Matching Program on the Web

The Resource Foundation for Children with Challenges has announced a new parent matching program available to parents of children with special needs. The free program will try to match parents of children with the same or similar disorder. To participate in this program go to the the Resource Foundation's Web site at http://www.therfcc.org/parent-match.html. Fill out the form and click on the "Submit to Parent-Matching Program" button. The Foundation will contact you by E-mail when they have found your match.

Nickelodeon to premiere NEW SERIES



Nickelodeon will premiere a groundbreaking new series focusing on a child in a wheelchair who refuses to let his disability define him. Pelswick, which will air October 24 at 8:00 p.m. (ET/PT), follows the daily life of the fearlessly funny title character who happens to be in a wheelchair.

The series was created by John Callahan, who has quadriplegia. Each episode focuses on how Pelswick confronts the issues that go hand in hand with growing up. The cartoon features Pelswick's colorful friends, including his two best friends Ace and Goon, and Julie, the girl of his dreams.

According to Callahan, "Kids will find that Pelswick, and by extension, other people with disabilities, are just people. They have friends, dreams, challenges, and frustrations just like anybody else. It's easy to relate to Pelswick because he faces real kid issues, such as fitting in and peer pressure."

Product Recall Information

The US Consumer Product Safety Commission (CPSC) and Gymboree have announced a recall of plush shape sorter toys. The toy is a multi-colored, plush fabric sorter box with six shapes that rattle, crackle or squeak, and have a multi-pattern design. The stuffing of the toys can contain sewing needles and sharp metal pieces. If you have this toy, stop using it immediately and return it to the store where it was purchased for a full refund. For more information, contact Gymboree at (800) 222-7758.

The U.S. Consumer Product Safety Commission protects the public from unreasonable risk of injury or death from 15,000 types of consumer products under the the agency's jurisdiction. To report a dangerous product or product-related injury, and for information on CPSC's fax-on-demand service, call their hotline at (800) 638-2772 or CPSC's teletypewriter at (800) 638-8270. Consumers can obtain this release and recall information at CPSC's Web site: http://www.cpsc.gov. Consumers can report product hazards via e-mail at info@cpsc.gov.

EP Board Member Appointed to AAP Committee

David Hirsch, MD, EP's "Ask the Doctor" columnist and member of both EP's Editorial Advisory Board and Board of Directors, was recently appointed to the American Academy of Pediatrics (AAP) Committee on Children with Disabilities. The Committee on Children with Disabilities studies and makes recommendations to the Board of Directors on the role of pediatricians in the long-term outcomes of children with chronic diseases and disabilities. This committee also advises the AAP on issues of the delivery of community-based healthcare services for chronically ill children who are technology dependent. According to Dr. Hirsch, "It is an honor to be selected to serve on this committee. It allows me to work more directly with other members of the AAP who have a special interest in children with special healthcare needs. I am particularly interested in the issues of transitioning adolescents and young adults with special healthcare needs into an appropriate adult healthcare system that recognizes the importance of maintaining a Medical Home and comprehensive, coordinated, family-based care.

VISIT OUR WEB SITE, WWW.EPARENT.COM, FOR UP-TO-DATE INFORMATION ON THE WORLD CONGRESS AND EXPOSITION ON DISABILITIES.

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Circle #60

"No Body's Perfect, Everybody's Special"

The Attainment Co., 1998
Running Time: 20:30
Available through the EP Library: (800) 535-1910;
Code: AC019GN
Cost: $89.99
plus shipping and handling

NO BODY'S PERFECT...
OLIVIA
TRISTAN
EMILY
EVERYBODY'S SPECIAL!!

This video is designed to teach children to understand what it means to have a disability. The tape, along with accompanying lessons and activities, lets children know it is okay to be different. It shows children with disabilities adapting to their lives and doing the things that typical kids do.

This live-action video program features three real-life young people, Tristan, Olivia, and Emily who have disabilities. Tristan is a 6-year-old who has a hearing impairment. He attends public school and has teachers who are helping him learn sign language, lip reading, and speech. He loves doing all the things other six-year-olds do: biking, swimming, playing sports, reading, and watching television. Olivia is an inquisitive, energetic first-grader. She has a visual impairment, but she does not let that slow her down. With the help of some vision aids, she attends school, reads, watches TV, and plays with her friends. Emily lost her right leg below the knee in a farming accident when she was 22-months-old. Now in fifth grade, Emily uses a prosthesis and participates in basketball, soccer, swimming, and has fun with her friends.

The three friends, along with a character named Jack, a "Mechanic of Misconceptions," try to educate people and correct any misunderstandings that others may have about people with disabilities. In the video, Tristan, Olivia, and Emily talk candidly about health conditions that make them special, and yet in many ways, very normal. Through interviews and day-in-the-life video footage, the three youngsters communicate a mixture of health facts and demonstrate how they live with a hearing impairment, a visual impairment, and a prosthesis. In their own words they send the message that "No Body's Perfect, but Everybody's Special."

The video may be viewed in its entirety, or each segment may be shown separately and time may be taken for discussion and activities. The educational objectives of this video are to:

- identify and acknowledge special health conditions;
- increase awareness and acceptance of people with disabilities;
- understand differences as well as similarities in others.

This program, comes with a 54 page teacher's manual that lists objectives for each lesson, dispels common myths about disabilities, has a glossary of terms, and contains activities for children to engage in to reinforce each lesson. The activities are meant to help the children understand what it is like to have a disability. One activity involves students playing charades to understand what it is like to communicate without speaking. The children work in pairs and try to communicate an idea silently, using only hand gestures. To simulate a physical disability students tie their arm to their side and must keep it that way for the entire morning. The students are asked to write about what it felt like and any difficulties they encountered using only one arm, as well as what adaptations they made. Another activity involves researching and writing on famous people with vision impairments such as Helen Keller, Ray Charles, and Stevie Wonder.

The manual also includes fun hand-out sheets such as a word search puzzle, a braille chart, and an American Sign Language chart.

This program is appropriate for children in grades 1-8.

The Road To Atlanta

NOVEMBER 10-12, 2000 • WORLD CONGRESS & EXPOSITION ON DISABILITIES

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Shire Richwood, manufacturer of Adderall® (mixed salts of a single-entity amphetamine product), a medication for the treatment of attention deficit/hyperactivity disorder (ADHD), is proud to be a sponsor of the World Congress and Exposition on Disabilities this November. Our participation in this event is part of our ongoing commitment to help children with ADHD succeed in school and in life, and to support families affected by the disorder.

"Being part of the World Congress and Exposition on Disabilities is important to us because it is a powerful forum to help people understand that while ADHD is a serious disorder, it can be effectively treated," says Stefan Antonsson, senior vice president for marketing at Shire Richwood.

ADHD can have a profound impact on children and adults who have the disorder, as well as their families, friends, and caregivers. People with ADHD experience inattention, hyperactivity, and impulsivity that can significantly impair their ability to function in school, at work, or at home. ADHD affects approximately 3 percent to 5 percent of all school-age children in the United States, and is considered the most commonly diagnosed psychiatric disorder in children and adolescents. In addition, up to 66 percent of children exhibit symptoms into adulthood.

As we work and talk with people who are affected by ADHD, we at Shire Richwood see the devastating effects the disorder can have. This understanding drives our commitment to educating the public about ADHD diagnosis and treatment, conducting ongoing research into new ways to help people with ADHD manage their symptoms, and building relationships with families, physicians, and teachers, as we work together to support ADHD patients in every way possible. By nurturing greater understanding of this disorder, our goal is to remove the stigma from ADHD and its treatment, so that more children and adults with ADHD can get the help they need.

Shire Richwood supports countless educational initiatives, including ADHD workshops at state PTA conventions that help parents and teachers tackle the problems that ADHD can cause in school. In addition, each September, Shire Richwood conducts ADHD Experts On Call, a three-day telephone program where people from around the country can speak one-on-one with leading experts in the field of ADHD.

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Models of Excellence
in EDUCATION

This year's Models of Excellence in Education celebrate inclusion—in the classroom, on the job, and in the community. We have heard from schools that have welcomed children with disabilities into their classrooms and their lives; programs that teach both children and their parents; students who act as advocates for their classmates; and students with disabilities who learn job skills at school and go on to become valued members of the workforce. Inclusion is a word that is often used in the special needs community. It is wonderful to see this word put into action through the hard work of so many caring individuals, teachers and students alike. In addition to specific educational programs, we have also received a number of tributes to teaching professionals. We have included them here as "Exceptional Educators." We invite our readers to continue to thank teachers and other special professionals by sending in their nominations for Exceptional Professionals. Thanks to everyone who participated in submitting their nominations, and congratulations on outstanding programs!—The Editors

Harold Schnell Elementary School • West Carrollton, OH

Nominated by Barbara E. Shanahan

EXCEPTIONAL
EDUCATIONAL
PROFESSIONALS

Above and Beyond

Schnell Elementary School has done an excellent job in accommodating my daughter Emily, 11, who has cerebral palsy, and investing in her education from the first day of kindergarten.

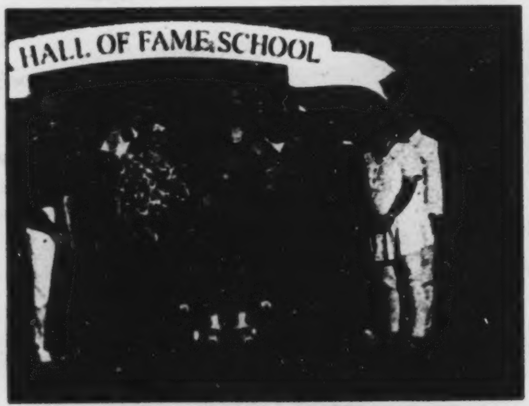
We all have learned so much from each other. They have provided Emily with a toilet seat, ramps for access to recess time and for emergencies, a laptop computer, printer, software, scanner for class assignments, a stander, and more. Emily is in the classroom full-time and has achieved A's and B's. The occupational and physical therapists come in to advise for positioning concerns and valuable adaptive ideas for use in the classroom. We provided her desk from home.

At the start of each school year, homeroom teachers have taken Emily into their classes (wheelchair, desk, and stander) with the same level of expectations as they have for other students. The teachers have soared with adaptive ideas for Emily in the classroom. When Emily has struggled with a concept or subject, the teachers go the extra mile to help Emily gain the self-confidence needed in order to apply the material being taught. The teachers hold meetings and talk honestly with us as parents on areas where we need to let Emily do more for herself for greater independence.

During the IEP, we state that Emily should be in regular classes for art, music, and gym. We leave it up to the teachers how classwork can be adapted for Emily. With the help of her attendant, Emily creates art and learns about its history. With the help of a friend, Emily played a solo song on a recorder. In gym, she plays soccer and actually made a goal with her wheelchair! Mr. Stebbins and Mrs. Hulgan take Emily out of her wheelchair to do therapy exercises and reward her with pizza coupons. Emily tried out for Student Council Representative and won in both second and fourth grade. She served as an alternate on the Student Council in the third grade. At the start of 5th grade, Emily tried out for Safety Patrol and has served throughout the year in the mornings every other week.

In December of 1995 Emily had hip surgery and was in a body cast for 8 weeks. The Schnell staff welcomed Emily in class the whole time she was in her cast! Emily did not fall behind in her studies and her days were not so long while in the body cast, since she could attend school.

I am thankful for Mrs. Phiffner and Mrs. Hill because they were able to identify Emily's learning style and strengths. They see Emily as a student with potential.



Front row (l-r): Mrs. Langley, Mrs. Hulgan, Emily Shanahan, Mrs. Lightcap, Mrs. Stotts, and Mrs. Montgomery. Back row (l-r): Mrs. McDougall, Mr. Stebbins, Mr. Alexander, Mrs. Phiffner, Mrs. Hill, Mrs. Carlisle, Mrs. Gardeckl, and Mr. Smith.

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Phoenicia Elementary School • Phoenicia, NY

Nominated by Debra Lloyd

Willingness, Team Spirit, and Awareness at Phoenicia Elementary

Two years ago I nominated Phoenicia Elementary School as a model of excellence for inclusion. They had been preparing for my son, Joshua, who has Leigh's disease, uses a wheelchair, is non-verbal, and has bilateral hearing aides. The district had never had such a medically and physically involved child before, so a lot of renovations needed to be accomplished to make the school more accessible. They never once said, "This is too expensive," or, "He would be better off in a special school." What they did say was, "We are scared, but we will give it a try." The district couldn't have met the challenge any better. There have been glitches, of course, but nothing that could not be fixed. They renovated bathrooms, put in a ramp, provided CPR training, and educated the staff on children with Leigh's, Josh's limitations, and how best to interact with him. They plan to make playground accommodations and access to the auditorium stage.

Two years ago when I was talking to Randy Collins (the principal) about the renovations, I asked, "If Josh doesn't make it to kindergarten, will you regret the work?" No, he wouldn't regret the work, he told me; these things are things that should have been done years ago. He really "gets it."

In September 1999, Joshua started at Phoenicia Elementary School, fully included in kindergarten. He has a one-to-one aide, Melissa Rebock, in the class and in after-school activities. He receives all his therapies at school, including consultant teacher services with Joanne Bachor. Melissa and Joanne, along with the regular education teacher, Heidi LaMonda, are the center of Joshua's team. With the help of PT, OT, and ST, they have adapted activities in so many imaginative, wonderful ways that Joshua does everything that the other kids do. Along with all this they also find the time to educate the children and staff on respect for people with disabilities.

Phoenicia School has been known within the district as the school for inclusion, and in my eyes they have moved up a level for willingness, team spirit, and awareness. I'd like to say "thank you" for making my little boy's life as normal, happy, and filled with love as possible.

Quest Kids • Orlando, FL

Nominated by Stacy Millard and Wendy Zeballos

A Foundation for Inclusion

Often, parents of children with special needs find themselves without the necessary supports. People say, "It takes a village to raise a child." For a family who has a child with special needs, Quest Kids is that village.

Quest Kids helps children up to age 18 with autism and related disabilities exceed expectations. Our program utilizes applied behavior analysis techniques (using behavior principles to solve practical problems) to help children learn a variety of skills. We work to integrate school, home, and community experiences into a comprehensive program for each individual child.

We build a strong foundation for learning, giving our children tools to communicate and be successful. On top of this foundation, we teach self care and life skills (from potty training to preparing a meal), social skills, academics, and the ability to make choices. The staff at Quest Kids are always working to make the children as independent as possible.

Learning together at Quest Kids.

Parental involvement in all aspects of the therapy is strongly encouraged. Parents and professionals work side by side to determine both short- and long-term goals that are functional and attainable for the child. In parent training sessions, parents learn positive approaches that help to decrease inappropriate behaviors and teach new skills. Staff members will even visit parents and their child at home or in a particular place (e.g., the shopping mall) where their child needs support.

Quest kids offers support for families to help children integrate into the community. We help children successfully transition into schools with the goal of placing them in the least-restrictive environment that supports their growth. Community training includes having "practice" doctor visits, recreational activities, or family gatherings. Children with disabilites can often become isolated. One of the goals at Quest Kids is to give children the opportunity to be included and be with other children in the community, at the playground, or in the classroom. With practice sessions and repeated exposure to these settings, children are integrated slowly and more successfully.

Through creative teaching strategies and a child-friendly environment, children learn, love, and grow. First steps are taken, first words are spoken, and we are thankful every day that parents allow us to be a part of the journey.

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Children's Learning Center • Brooklyn, NY

A Warm Welcome for Two Young Girls

Monique Moffat is all smiles at the graduation ceremony of the Children's Learning Center, June 2000.

Monique Moffat and Cathy Wu, both 4 and blind since birth, have attended the Children's Learning Center (CLC) at Helen Keller Service for the Blind since infancy. But two mornings a week, the girls play with dolls, enjoy circle time and paint with sighted preschoolers at the Brooklyn Heights Montessori School (BHMS), Brooklyn, NY.

This inclusion project was conceived by Garth White, the principal of CLC—the only school of its kind in Brooklyn. Mr. White sought out a Brooklyn preschool where Monique and Cathy could meet sighted children and become familiar with the kind of independence that will be expected in kindergarten.

"Our program confirms my belief that children with disabilities can succeed in mainstream settings," says Mr. White.

Last January, Mr. White, BHMS Preschool Director Susanne Peebles, and teachers from both schools spent two months planning how the program would be implemented. Before Monique and Cathy came to school, Mr. White visited the children at BHMS to show them how a cane is used, let them type words on a Brailler, and answer questions.

"The Montessori philosophy of allowing children to learn from each other and use hands-on materials to teach practical life lessons lends itself very nicely to visually impaired children," says Ms. Peebles.

Monique's mom, Hermina Moffat, says,"Monique began attending the CLC at Helen Keller Services for the Blind when she was one year old and has made tremendous improvements. Because of the inclusion programs at BHMS, she's become independent and no longer wants assistance with anything—as she had in the past. We do not treat her like a child with a visual impairment. She has become an active member of our family. She is included in all things."

Cathy Wu is congratulated by New York State Lt. Governor Mary O'Donohue at the Children's Learning Center graduation.

The Professional Center for Child Development • Andover, MA

Nominated by Ellen McGrail Stevens, MEd

Providing Early Opportunities for Children with Special Needs

The Professional Center for Child Development was started 27 years ago by two forward-thinking and talented women. Cynthia Stocking and Veryl Anderson became aware of the need for a preschool educational center for differently abled children in the area. The pair of nurses were dedicated to providing families with special needs children, ages birth to 7 years, a place where they could receive coordinated medical, therapeutic, educational, social, and referral services. Cindy and Veryl were young mothers who saw all kinds of opportunities for "typically developing" children, and wondered why not provide an option for the not-so-typical child.

Today the Center is still helping parents, children, and the public, while offering services that enable children to begin life on a path that will promote the achievement of their full potential. The Center offers: An Early Intervention Program, a 766-approved private pre-school, community developmental play groups for children of all abilities, pediatric therapy, parent groups, and a regional consultation program.

As a parent of a graduate of The Developmental Day School, I was able to see, first hand, the vision of those exceptional founders played out each day. My son Timothy thrived in the environment of professional care and concern. Timmy has cerebral palsy, a seizure disorder, weak bones, he does not walk or talk, and has profound developmental delays. Timothy attended the Day School for four years. The staff was able to help my family understand and provide for the needs of our child. There was a time when I brought Timmy into school after hip surgery. He was in a full body "spika" cast and was not very happy about it. His teachers, nurses, and therapists worked with us to help him through this difficult time. It was in these early years he was given the intervention that I truly believe has helped him to become a happy and healthy eight-year-old. Timmy has moved on and now attends school in a collaborative.

Ellen McGrail Stevens' son Timothy thrived at the Professional Center for Child Development.

I think about the great gift Mrs. Stocking and Mrs. Anderson gave to the families north of Boston. They took a dream and turned it into a successful, non-profit community service agency.

975

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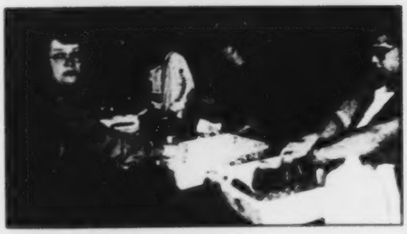
West Lyon Community School • Inwood, IA

Nominated by Brian Brands

Snack Pack



Snack Pack members work as a group and develop skills they can use in the workplace.

Fifteen years ago an exemplary program was initiated at West Lyon Community School called "Snack Pack." The Snack Pack organization is available to all West Lyon students in grades 7-12 who have some disability and receive special education services. Nearly all students who are eligible to participate do so.

Part of West Lyon's philosophy is preparing students for the real world. Snack Pack teaches students many skills that they will use during their acadmeic careers and after.

The group plans, prepares, and serves concessions at athletic events at the school. It serves as an avenue for our students to generalize information learned in the classroom and to develop and practice social and job skills needed in the work place.

Snack Pack members nominate and vote for officers and divide the membership into work groups that are responsible for each phase of a Snack Pack concession. These responsibiliites include: planning, purchasing, pricing, advertising, preparing, setting up, selling, and cleaning up. Students experience each phase of the operation throughout the year. Parents often participate selling at concessions.

Students participating in Snack Pack decide on the menu, compile a grocery list, and shop for groceries. After the groceries are purchased, the advertising group designs posters and announcements to publicize the event. In math class, students compute the cost of supplies and decide on a fair but profitable selling price. Students use that skill when selling the products to customers. While working in the concession stand students learn to work cooperatively and to treat customers with respect. The Snack Pack treasurer is responsible for depositing the money, paying bills, and preparing a monthly statement for the members.

The Snack Pack members have planned, purchased, and delivered the various items involved in charitable giving. Snack Pack fosters group responsiblility and shared decision-making.

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Thomas Paine Elementary School • Cherry Hill, NJ

Nominated by Mary Engelman

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"See You Next Year!"

Peggy Lithgo's class at Thomas Paine Elementary School.

For the students with multiple disabilities in Peggy Lithgo's class at the Thomas Paine Elementary School in Cherry Hill, NJ, inclusion is a two-way street. Innovative programming has attracted the attention and enthusiasm of the school's entire student body and staff. The hallway outside Peggy Lithgo's classroom features an enormous "Friendship Quilt" wall hanging, a collaborative effort involving families, friends, staff, and students. The class abounds with activity when students have their daily visits from student "recreation mentors," shared activities with non-disabled peers, and special projects. Peggy Lithgo's students also participate in community service activities and field trips.

During the annual science fair the children explored the longevity of different brands of batteries. Their "You Light Up My Life" project involved purchasing five different brands of common household batteries and five colored flashlights. For two weeks, the students enjoyed daily sensory integration activities using their individual flashlights. Information about battery use was collected and charted, then presented during the evening fair. The results were surprising. The project incorporated a variety of educational goals, including visual discrimination, communication, sensory integration, and tactile stimulation.

Earlier in the year, their class hosted a Halloween "haunted house" for the entire school of over 400 students! The result was a wildly popular holiday attraction that gave every student in the school, regardless of age, an opportunity to meet the class, openly explore their room, and also enjoy a sensory integration challenge of their own!

Later in the fall, the class hosted a "Thanksgiving Feast" for the support personnel involved in their programs. Even bus drivers and aides attended the thought-provoking event, along with therapists, school staff, and family members. To look around the room and see the many people directly involved on a day-to-day basis with the students impressed everyone. It also created a casual opportunity to exchange information, anecdotes, and experiences. Bringing together so many disparate individuals early in the year established lines of communication that subsequently evolved throughout the year.

Fifth grade students eagerly assisted the class during scheduled visits. What clearly evolved during the year's many shared projects was a mutual enthusiasm among the students. This bond was nowhere more apparent than at graduation in June, as the students shared their last day at Thomas Paine. Following a special graduation observance for all fifth graders, the students took home not only certificates, but special hand-written messages from the many children who had shared special projects and experiences.

The most poignant message was also the most spontaneous: "See you next year!" The class will transition to middle school, along with all other graduating fifth graders, in the fall.

977

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Inglewood Unified School District Preschool Pathways
Inglewood, CA

Nominated by Diana Bowlby

Inclusion for the Whole Family

Children enjoy play time at the Family Resource Center, part of the Inglewood Unified School District.

The Inglewood Unified School District Preschool Pathways Program encompasses all of the district's preschool special education programs. One of the most important aspects of our program is the collaborative relationship we have with the Child Development Center (CDC) and Head Start preschools located in our district. Due to this collaboration, we are able to provide a full inclusion program for over half of our preschoolers identified as requiring intensive services, and we are also able to provide services to typically developing preschoolers and their parents.

At this time we have 29 students attending our preschool special day class and 36 students attending Head Start programs and the CDC program located in Inglewood. The students who are fully included have disabilities such as autism, Down syndrome, Sotos syndrome, developmental delays, severe language disorders, orthopedic handicaps, and other significant health problems.

The students enrolled at Head Start and CDC programs receive special education services on a watch-and-consult basis. Our resource specialist teacher and special day class teacher go into the general education preschool classrooms at least once a week to work with the identified preschoolers, give suggestions, demonstrate techniques to teachers, and help track the progress of each child. With this arrangement, the teachers are able to provide assistance on an as-needed basis.

Our collaborative relationship with the CDC and Head Start program also enables us to provide services to the typically developing students and their parents. By working directly in the Head Start and CDC classrooms the special education teachers, speech and language pathologists, and special education aides can give assistance to children who are not identified as having special needs through consultation with parents and direct services. The resource specialist and the speech and language pathologist are available to hold student study team meetings to discuss concerns with the parents of any child enrolled in the program. In addition, next year one of the speech and language pathologists will provide language development groups for all the Head Start students.

The heart of the preschool program is the district Family Resource Center, which is located at the preschool annex. The Family Resource Center provides parents with videos, books, handouts, and a friendly and knowledgeable assistant to answer questions and make referrals. This resource is available to all residents in the district.

Our pride in our full-inclusion program stems in part from the excellent progress our students are making in the Head Start and CDC classrooms. Our preschoolers blossom when they are able to work and play side-by-side with typically developing peers.

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Educators and Therapists

Nominated by Pamela Frank

EXCEPTIONAL EDUCATIONAL PROFESSIONALS

A Tribute to a Special Group of Caregivers

This is to pay tribute to the unsung heroes of children with disabilities who dedicate their time, energy, and abundant love to make a better life for those who are too often "left behind" in the community. These unselfish givers are the educators and therapists.

Parents alone find the care of such a child overwhelming. Inevitably, a successful outcome is the result of combined effort by those skilled in overcoming obstacles with positive measure. They are partners whose intense personal efforts reflect a group's commitment towards developing a child into a participant rather than a spectator in his or her community.

As I sat in a meeting about my son Doug's IEP (the Individualized Educational Plan required by the state for all identified students with disabilities), I looked around at all these caring persons who are pouring their daily dedication, expertise, and love into my child! I was so touched knowing that we all share him. Every success elicits huge "hurrays!" Every set back, a mutual grave concern.

Pamela Frank's son, Doug, age 14.

Whether or not we all agree on the decisions we are facing, is not as important as doing our best to help a child who is struggling to do more than his best to survive. We can all learn from him!

It has occurred to me that too many times I have walked away from these IEP meetings feeling negative emotions—failure, hurt, disappointment, etc. I do not remember ever thanking the others on my son's team for their part, their emotional and practical input, or their preparation for the meeting.

So to all of you heroes in the community who do so much for these students who mean so much to their parents, I want to say an emphatic "thank you!" for all the appreciation we have felt and so often feel but have not expressed. Your hard work is evident in our children's daily progress.

This letter is to express appreciation and recognition for a special group of dynamic caregivers, not just for my family and son, but for all whose lives are touched and improved by their sacrifice, compassion, and unconditional love.

Norris Road School for Special Education • Tyngsboro, MA

Nominated by Cheryl Pillsbury

EXCEPTIONAL EDUCATIONAL PROFESSIONALS

A Special "Thank You"

My daughter Alicia has mental retardation, PDD (pervasive developmental disorder), autism, and an unknown muscle disorder.

When she was diagnosed at age two, she started in Project Beam. They were wonderful and a great pleasure to be around. They made you feel at home and not alone. They helped and guided us. They showed me a new road and a brighter light. I never saw a happier or more excited child, always wanting to do something new.

Now, Alicia attends the Norris Road School for Special Education. In seven months, Alicia has learned to speak, use pictures to talk, ride a bike, and do three jobs in school. She can point, draw, play with play dough, and climb stairs. I'm amazed and thrilled for what these teachers have done. There are no words to describe the joy I feel for Alicia. Melissa, McKenzie, Judy, Lynne, Patty, Suzanne, and Carolynn work as a team among themselves and with us. We work together for Alicia's education, welfare, and security at school and at home. We use the telephone and a communication notebook to stay in touch with what happens at school and at home.

Not only are they teachers, they are parents and friends who are great listeners.

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West Portal Elementary School • San Francisco, CA

Nominated by Talya Fishman, Judy McEvoy, and Amy Mack

Learning About Inclusion—In and Out of Class

In trying to understand why and how inclusion works so well at West Portal Elementary School with 600 K thru 5 students from diverse ethnic and economic backgrounds, parents of students who benefit from inclusion point to particular programs that the school has introduced, and to the educational philosophy and personal qualities of the principal.

"Lunch clubs," small groups in which an inclusion student works on social and communication goals while playing with a group of same-age peers, are so popular that classmates sign up weeks in advance to participate. The inclusion support specialist and paraprofessionals spend many after-school hours in rehearsal and practice so that students can participate in the school musical, play in the band, and be part of the kickball team. A third-grader with CP whose profound anxiety about riding on public transportation would have prevented her from going to the symphony with her class, had brief, weekly "deconditioning" excursions months before the scheduled concert.

Jessica, (left) a student at West Portal Elementary, and her peer buddy.

Under the inclusion support specialist's supervision, two 5th graders with Down syndrome hit the main shopping street once a week. They each brought a friend to the pizza parlor, practiced making social introductions, learned to make a purchase, counted change, used a pay phone, and left messages on answering machines. The students and inclusion support specialist reported on their community-based instruction activities in a lecture and slide presentation at TASH (The Association of Persons with Severe Handicaps).

Principal Jeanne Villafuerte impresses upon all staff members that differences are not to be pointed out. Every year three hours of staff development time are devoted to "Abilities Awareness;" guided by PT's and OT's, teachers get an inkling of frustrations that are routine for many students with special needs. General education teachers are encouraged to "take ownership" of students in their classes and not wait for the support specialist or paraprofessional to address problems that arise. The school openly acknowledges the delicate balancing act that general education teachers face: the need to give attention to the inclusion student without detracting from the class as a whole.

Friendly Faces Program—Independence Middle School • Bethel Park, PA

Nominated by Cindy Pyszka

Sharing Companionship with a Friendly Face

Jan Brodzinski, a special education teacher at Independence Middle School, has developed a wonderful program called Friendly Faces.

Mrs. Brodzinski teaches children with autism at the school. The students attend some mainstream classes as well. Mrs. Brodzinski felt that the students should have an opportunity to interact with their typically developing peers. In the fall of 1999, she met with 141 students on team 7C, which includes her students. She briefly described autism and asked for volunteers to spend time with the students. She was delighted when more than half of the team signed up. She posts a schedule at the beginning of each month, rotating the 75 students through her students' class. At least two Friendly Faces volunteers usually come, so each student has a companion.

Sara Pyszka (center) is a Friendly Faces volunteer. With her are speech therapist Amy Caloiero (left) and paraprofessional Diane Jacobson (right).

The students share lunch several times a week, enjoying companionship in a small group setting. The kids are again joined at the end of each day by Friendly Faces students who engage them in fun activities and an end-of-the-day snack.

Mrs. Brodzinski and the parents of the students say the exposure has helped the students come out of the shell autism often builds around the person. More than anything, the students with autism are accepted and greeted by name by the Friendly Faces Friends.

One Friendly Faces volunteer says that while he knows his volunteer work helps the students, he feels it helps him as well. "It's kind of like I'm helping them, but I'm helping myself also. It's teaching me that just because they are a little different and they have autism, I don't have to treat them any differently than I treat anyone else."

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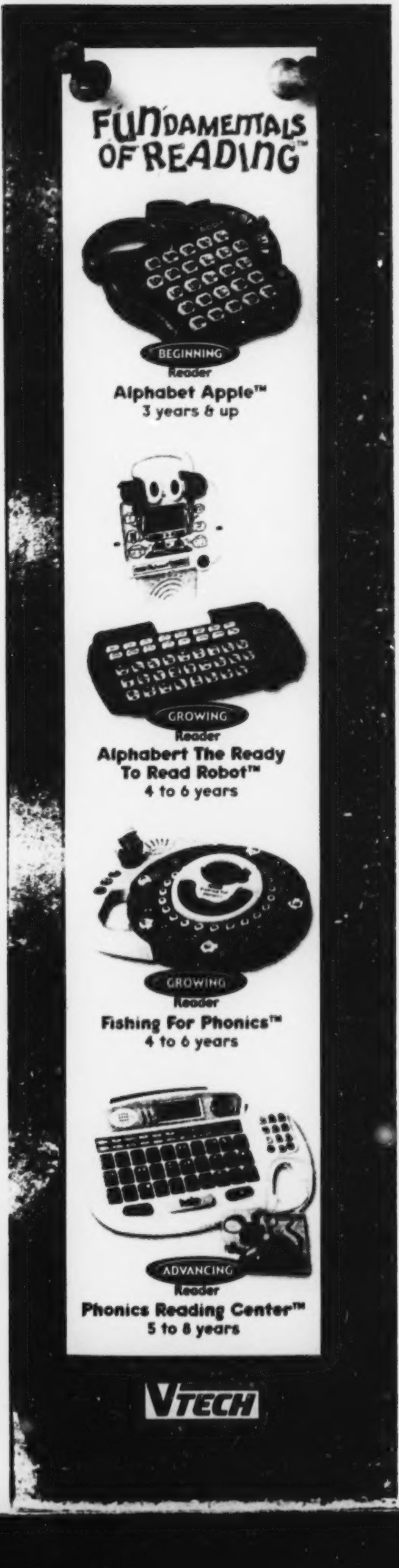

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Sue Newburg, Banting Elementary School Waukesha, WI

Nominated by Anne Juhlmann

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Intuition Plus Understanding Equals a Very Special Educator

I would like to tell you about a special educator who is indeed very special. Her name is Sue Newburg and she was the early childhood teacher for my son, Zachary, and my daughter, Abby. I first met Sue when Zachary had just turned 3 and was about to transition from birth-to-three services to school-based services. I was confused, frightened, and sad. Though Zachary had been ill from the age of 2 months, I was not prepared to let my child enter this new phase in life. It was a rude awakening to me when he turned three and his challenges of neuromuscular disease, autism spectrum disorder, and pseudo-obstruction syndrome had not disappeared.

(L-r) Abby, Bryan, Zachary, and Jami are students at Banting Elementary School. All four children have been taught by Sue Newburg.

I had a very hard time sending Zachary to school. Lou, my husband, and I consented to a mere two days per week, although the district had recommended he attend full time. Sue Newburg respected our choice. She is committed to listening to families and what they want for their child. She is careful not to superimpose her own philosophy or vision on top of that of a family. Her knowledge, attitude, and experience are an unbeatable combination.

The next year I brought my daughter Abby to the school for the 3-year-old screening. Abby had received extensive early intervention for undiagnosed developmental delays. We decided to try her in a regular preschool. Abby did very poorly there socially. She was a very verbal, funny, personable child in our home but would not let anyone see this. Abby did poorly at the screening and it was recommended that she have a week of evaluation in the early childhood classroom. We assumed she would be formally placed. Sue offered to do the week-long screening for us because Abby knew her and we felt Abby would do better in a more familiar environment. Abby ended up being the delight of all those who tested her that week. She was herself, the way we knew her at home! For once, someone outside the family could see our joyful, capable child. Needless to say, Abby was not formally placed. But there is no doubt in my mind that she would have been if anyone else had evaluated her.

Sue never ignored Abby's needs just because she did not have an IEP. She just saw Abby as a special little girl who needed her help. This year Abby is a peer model in the 4-year-old class, and has retained all of the progress she made last year.

It is not too dramatic to say that my children's lives are forever better because they knew and were loved by Sue. Nor is it an exaggeration to say that I am a better mother for knowing Sue. I have learned so much from watching her and listening to her. The qualities that make Sue Newburg such an exceptional special educator can only partly be learned in school and through experience. What makes her exceptional is her intuition, understanding, and ability to look inside a child and past his or her outward behaviors.

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Desert Willow, Vale School District • Tucson, AZ

Nominated by Caryn Plummer

Inclusion Is a Top Priority at Desert Willow

Bryce Plummer and his kindergarten classmates getting ready for their school's performance of "Temples and Tombs."

"Children do not have to earn the right to be in a classroom at Desert Willow, they just have to show up." This is the philosophy in the Vale School District and at Desert Willow, the elementary school my son attends in Tuscon, Arizona. This philosophy means that exceptional children are placed in typical classrooms with the support for success. The way this philosophy is integrated makes this school, as well as the entire district, a model of excellence.

For my son, Bryce, this means a full-time paraprofessional who monitors his academic progress, modifies his curriculum, facilitates interaction between students, and provides hands-on support. Bryce is encouraged to follow his peers' behavior and has learned to sit for story time and assemblies, line up at the whistle, use a quiet voice, eat in the cafeteria, ride the bus for field trips, and work at his desk. Like his classmates, Bryce has been Door Holder and Line Leader. He has friends who greet him and miss him when he's gone. At a recent PTA meeting, he was one of the many students recognized for exceptional progress. In June, Bryce graduated from kindergarten, complete with pomp and circumstance—and my happy tears.

The district is active in making this program exemplary by encouraging parental involvement and open communication between parents and the school. A new Parent Resource Center, developed and staffed by parent volunteers, will open this summer. The district regularly hosts meaningful workshops and training sessions to educate those on the inclusion teams: teachers, paraprofessionals, and parents. In fact, parents are consistently included as key players in their children's education and are encouraged to communicate with team members at any time.

Communication occurs, in part, through a daily notebook. Bryce's paraprofessional fills in both outstanding and ordinary happenings for each daily activity. This allows us to talk to Bryce about school and his friends, and also tells us what he had for lunch and how he felt. We, too, write back offering suggestions and/or telling events that happen at home. I don't need an IEP meeting to know of Bryce's progress, and can contact any of his therapists with concerns, questions, or special milestones.

Bryce and a classmate share a hug.

The philosophy of inclusion at Desert Willow carries over into the community. For our family, inclusion means the ordinary events of life. It means that we have neighborhood teenagers as baby sitters—like everyone else. This year, Bryce will ride the bus to school—like everyone else.

Of course, Bryce is not like everyone else and inclusion at Desert Willow takes hard work and commitment from the staff and district administrators. Every day, I know that Bryce is an important part of the student body. If I know it, Bryce does, too.

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All Kids Can! Obadiah Knight Elementary School
Dallas, TX

Advocacy Today for a Lifetime of Inclusion

Smiling faces at the All Kids Can! program, pioneered by the Arc of Dallas, at Obadiah Knight Elementary School. The VALUE Kids advocate for children with disabilities.

The Arc of Dallas' pioneering program, All Kids Can!, introduces and reinforces attitudes in young students that invariably set the stage for lifelong inclusion. This program accomplishes its goals by introducing an integrated curriculum into schools and organizations. The curriculum consists of first-hand experience, research, awareness, problem solving, reading, writing, statistics, innovative thinking, and relationship building. More importantly it provides students with the opportunity to develop their own strategies for advocacy and problem solving.

This last year, The Arc of Dallas piloted the All Kids Can! program in a joint effort with two different talented and gifted sixth grade classes at Obadiah Knight Elementary School in Dallas. The students and The Arc jointly funded and produced an interactive Web site that encourages Internet visitors to learn about people with disabilities and the concepts of respect, value, and inclusion (http://www.allkidscan.org).

This year's All Kids Can! participants expanded the project. They chose as a class to work toward solving the real community problem of exclusion. After naming themselves the VALUE Kids (Valuing All Lives, Understanding Everyone), they dedicated their school year to advocating for the respect and acceptance of people with disabilities.

In order to spread their message, the students had to learn as much as they could about the community problem of negative attitudes and segregation, go through the problem-solving process, and work toward a real solution. The students generated a variety of ideas to apply toward reaching their goal. After evaluating their ideas, the VALUE Kids embarked on a series of awareness projects. The results were tremendous!

The VALUE Kids created and performed a skit to convey their message of inclusion; created the concept and logo for VALUE Kids; wrote letters to the editor of a local newspaper that published a derogatory article stereotyping people with mental retardation; and volunteered at the preschool at the local United Cerebral Palsy. During March, the students launched a Silver Ribbon Campaign at the Dallas City Council, the local chamber of commerce, and their school. They recruited 25 teachers to teach a developmental disabilities awareness curriculum developed by The Arc for a week during Developmental Disabilities Awareness month. More than 500 students participated. And finally, they secured the free production of a documentary video of their experiences to foster an attitude of inclusion and encourage others to participate in their own All Kids Can! project. Parents supported the project by allowing students to take numerous field trips, by raising funds for out-of-town trips, and by also learning about the needs of people with disabilities.

All Kids Can! schools make school "cool" for people with developmental disabilities, yet it goes beyond in teaching lifelong lessons about inclusion. After experiencing the phenomenal success of the All Kids Can! program, The Arc is actively marketing the program to many other schools and organizations and has made it available in a variety of lengths and formats at little or no cost to participants. Each program can be customized to fit the local school's or organization's needs.

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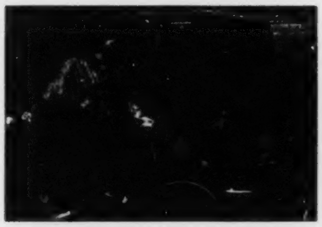

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Circle #34

Talents Unlimited Program,
Syosset Central School District, Syosset, NY

Enrichment Across the Board in Syosset

Syosset Central School District has expanded the role of teachers of gifted students to use some of their teaching methods to motivate children at different levels of learning, including students in special education classes. A nationally validated program called Talents Unlimited is one of the tools the teachers use.

Two children in the Talents Unlimited program enjoy their visit to the Syosset Firehouse.

"Syosset is very fortunate to have the support of a Board that greatly values education, and a community that deeply cares about its children," says Superintendent Dr. Carole G. Hankin.

The enrichment program teaches Productive Thinking, Forecasting, Communication, Planning, and Decision Making. Originally identified as the talents needed by adults to succeed in the work force, the talents are taught in a way that students can use them in their everyday schoolwork, as well as apply them to life situations.

Students respond with great enthusiasm, explains Dr. Hankin, because they can see concrete results from using their "newly identified" talents. "Making children aware of their thinking processes leads to higher-level thinking."

One example of the program in action was a project undertaken by Syosset's first- and second-grade special education students who learn in a self-contained classroom. The students were recently given the challenge to use their talents to enrich their own social studies curriculum, specifically when studying their own community. The objective was to show them how they could make certain things happen for themselves in school, and how by using their talents they could shape their own lesson.

The school's enrichment teacher helped the classroom teacher to devise some decision-making charts that would help students make their choices. In keeping with the lesson of their community, it was decided that the students would like to ask questions of an important figure in the community, someone who would know a great deal about Syosset. They came up with a list of individuals who filled specific roles in the community.

The students were asked to use their analytical talents to consider specific questions about each person. For example, would the person know a lot about Syosset? Did the person have an interesting job? Would it be fun to meet him or her? Answering each of these questions on a grid gave the students a graphic representation of their first choice. The class of nine boys decided the best person to interview would be Syosset's fire chief.

Next, their communication talents were called into play. The students together wrote a letter to the fire chief asking to interview him. Chief Favata invited the class to visit the fire station for a tour and to ask questions.

Barbara Nuzzolese, mother of Christopher, 6, is very happy about her son's participation in the program. "The trip to the firehouse was so wonderful for Christopher. It really brought together everything that they had been learning, and for the class to experience it together made it very special for him. I am very pleased with the integration of Christopher's class with the entire school, and the Talents Unlimited Program is a great example of how the children in the special education program benefit from all the resources of our school district."

Said their classroom teacher, "It was a wonderful experience for the boys, and it really helped to boost their self-confidence when they saw what they could accomplish by using their talents."

Dr. Hankin is satisfied that the assignment of an enrichment teacher to each of the district's seven schools has been a great addition to the curriculum. "Higher-level thinking and reasoning skills are valuable to students at every level of ability, and we are committed to giving our children every possible educational advantage."

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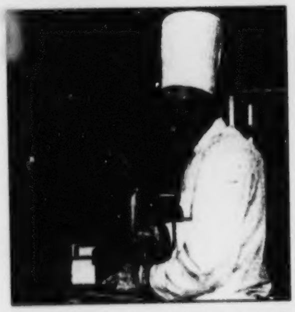
School-to-Career Program—
Atlantic County Special Services School District (ACSSSD) • Mays Landing, NJ

Nominated by Anne Dillon, School-to-Career/Transition Assistant

Working and Learning Side by Side, in the Community

High school students at the Atlantic County Special Services District in Mays Landing, New Jersey, report for class each morning by arriving at one of several businesses in the community. Their teachers greet the students at community locations such as a hospital, a nursing home, a college, hotel/casinos, grocery stores, restaurants, department stores, small businesses, and offices.



Learning on the job is part of the Atlantic County Special Services School-to-Career Program.

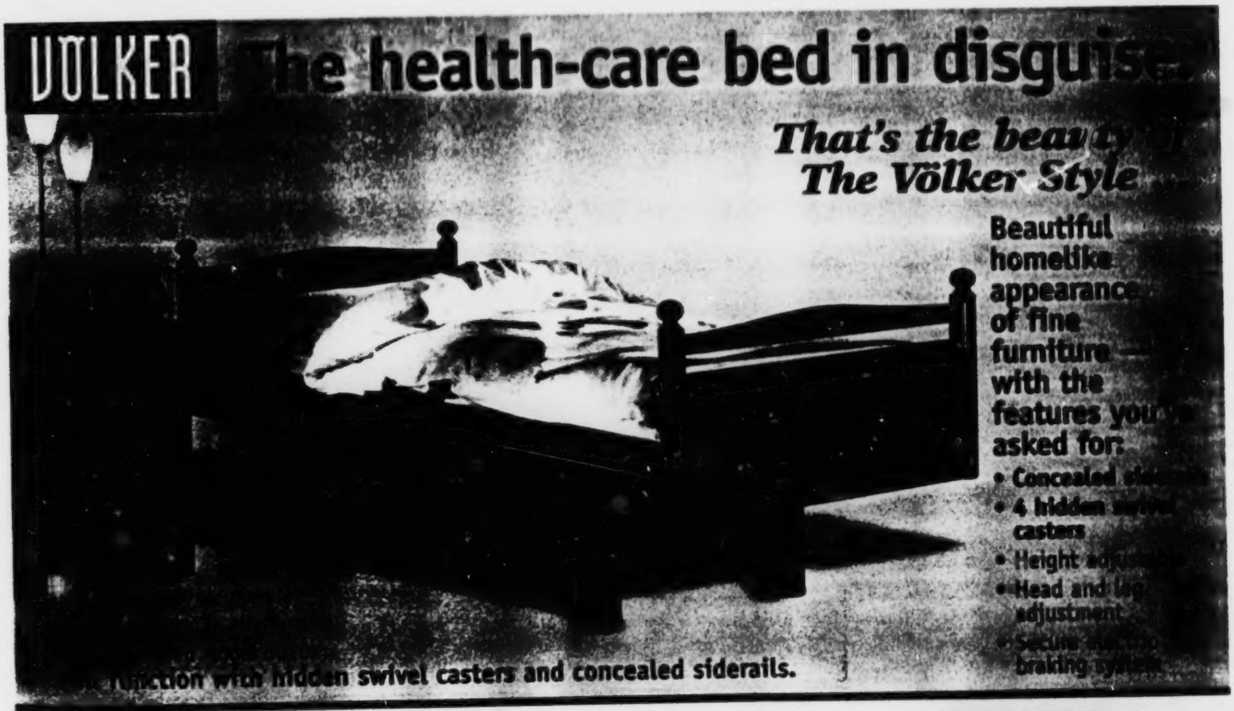
These students are participating in the final stages of a School-to-Career program, which teaches the skills necessary for successful transition from school to work and adult life to students with disabilities.

The School-to-Career program has three components: school-based learning, work-based learning, and connecting activities. School-based learning is the first step. Students aged 14 and older participate in the ATTAIN (Advocating the Teaching of Transition According to Individual Needs) program. Students choose career classes related to their interests. The emphasis is on providing students with work experiences in realistic settings and helping them develop good work behaviors and attitudes.

After initial preparation in the school-based component of the program, students have the opportunity for paid, structured learning experiences in the community.

A full-time teacher is placed at each site, to provide support to students, and to the work site employee mentors. The mentors are regular employees of the businesses that are chosen to teach specific job skills.

Job placement following the completion of students' IEP and graduation is about 70 to 80 percent. The district coordinates a countywide Interagency Transition Council that helps with the transition from school to work and adult living.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Moving Toward the Vision of the Universally Designed Classroom

by Lucinda M. O'Neill

CAST Director of Research, Dr. Bart Pisha helps an eleventh-grade student develop strategic reading skills using the CAST eReader and a specially formatted digital version of the student's textbook.

It is 10:30 on a Monday morning and the first grade teacher announces that it is "Drop Everything and Read" time. At the announcement, twenty-two children move to various locations in this inclusive classroom. Some of the students pick up a book from the library area and move to the rug, while others take a book out of their desks and begin to read. A few children go to the classroom computers, put on headphones, and select a book from a software program for kindergarten to third grade-level learners that offers numerous children's books in accessible electronic format.

All of the children are engaged in the reading activity, but each has his or her own approach. Some of the students use their fingers as a pointer to track the printed words, while others read the words aloud to themselves. A student who is blind reads a Braille version of the story she has chosen, created for her by her teacher using a scanner, digitized text, and an embossing machine.

Over at the computers, one of the first-graders follows along as the computer program highlights and reads aloud the words of the story he has selected. When the student gets to the end of the story, he begins again with the read-aloud feature turned off. Instead of listening to the computer read the story, he records his own voice as he reads the words aloud. Coming to an unfamiliar word, he clicks on it with the mouse, and the computer reads the word to him. Although this 6-year-old struggles with word decoding skills, he, too, can participate in the class reading activity and achieve at a successful level.

There is more than one way to become successful at reading independently in the UDL classroom. Using headphones, these students boost their reading skills by listening to stories as they read along on the printed page.

Seated in a wheelchair at the computer next to him, a girl whose motor impairments make it difficult for her to use a conventional keyboard, uses the software program's single-switch scanning feature to read the same story independently.

In contrast to both of his classmates, a precocious student at the next computer uses the software program to read a book for young readers. Setting the highlighting to a fast pace, he moves quickly through the book with little difficulty. While this student has many attention-deficit (ADD) characteristics that often interfere with his ability to focus in unstructured activities, by adjusting the program to his abilities, he, too, is successful in reading independently, .

In this universally designed activity, print-based text is not the only medium for learning, or even the preferred one. Instead, each student is encouraged to use the medium that works best for him or her, even when the goal of the activity remains constant.

Central to the effectiveness of this approach is the integration of technology into the learning environment. As a classroom tool, the computer can allow all students to achieve success in learning, including the struggling reader and the student with physical disabilities. With a variety of books available at different reading levels, both on and off the computer, students do not feel stigmatized when they are reading at one level while others may be reading at more advanced levels.

Much, of course, depends on the philosophy and approach of individual teachers. While most teachers have relatively little say over what curriculum comes into their classroom, they do have a great deal of control over how curriculum materials are managed and transformed into effective instructional practices. It is a challenge for the teacher to ensure that all the students in his or her class, regardless of their reading ability, are successful. Using an approach that draws on the concepts of Universal Design for Learning™ (UDL), this first-grade teacher manages to create a framework in which 22 students achieve success and improve their reading skills.

The first universally designed classroom

CAST's vision of the universally designed classroom began in the late 1980s with one student in an inclusive classroom. Matt, a kindergartner with cerebral palsy, could not talk or move any part of his body except his chin and eyes. Because he could not write or communicate verbally, Matt could do little to indicate his intelligence until CAST brought a computer into his classroom. By putting intelligence tests on the computer and hooking Matt up to an adaptive device that allowed him to operate the computer with his chin, CAST clinicians could demonstrate what they already knew—that Matt was a very intelligent youngster. "Our first idea was to provide assistive technologies," recalls David Rose, EdD, CAST's co-executive director. "But we soon realized it was a time-consuming and not very cost effective way of working with Matt. So we began to redesign the classroom materials."

When CAST created electronic versions of books for Matt to read on the computer screen, an unexpected thing happened. "Very soon all the children in the classroom were grouping around Matt and the computer. These kids wanted to learn to read and write the way Matthew was learning to read and write."

Over time, these early observations led CAST to the design and co-development, with a commercial software manufacturer, of a reading program intended for a mainstream environment with adaptations for individual learners built in. "Our work with Matthew taught us a lesson," Rose concludes. "If you are careful to design products that are good for students with special needs, these products are good for all students."

Moving toward the vision

While no classroom can yet claim to be fully universally designed, CAST has spent the last 15 years conducting research and demonstration projects in schools, both locally and nationally, which are designed to bring classrooms incrementally closer to the UDL vision. One such project, for example, teamed CAST with an educational publisher and Wakefield High School (Wakefield, MA) to develop a new technology-based instructional approach for students with learning disabilities. Called "The Strategic Reader," this research and development project combines the text-to-speech, highlighting, and study supports of the CAST eReader™ with a specially formatted digital version of an educational textbook to create an electronic textbook with embedded study supports. The study supports are designed to help students with learning disabilities differentiate key points from supporting details, and to effectively organize the information they find.

The Strategic Reader project demonstrates that providing classroom materials in accessible electronic format alone does not ensure accessibility for students with disabilities. Instead, it is often

continued on page 55

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necessary to provide a framework of multiple scaffolds and supports to help each student access the materials at hand and work at an individually appropriate level of challenge. A "scaffold" is a temporary support designed to bring the learning task within reach. This concept relates to the "zone of proximal development (ZPD)," a term coined to mean the optimal level of challenge, where the learning task cannot be achieved independently but can be achieved with support, neither too easy nor too hard. As learners progress, the ZPD changes, becoming a "moving target" that requires highly adjustable materials to support it.

To engage all learners, the universally designed classroom must include an array of programs and resources that allow students to work in their own ZPD, and that reduce the degree of support as their skills improve. In the case of the Strategic Reader project, researchers hope that the resulting instructional approach will not only increase students' access to social studies material, but will also help them develop effective strategies they can apply to all their reading. "The interactive instructional modules we're developing will teach the students how to identify key concepts by themselves," says Bart Pisha, EdD, CAST's director of research and principal investigator on the project.

In the universally designed classroom, teachers create a framework for success by responding to a wide range of learner needs.

What success would look like

The Strategic Reader project is one of several current programs supported by a new CAST initiative, the National Consortium on Universal Design for Learning. Under the direction of Grace Meo, MEd, this pilot initiative seeks to establish a consortium of schools dedicated to a common goal: implementing Universal Design for Learning in the classroom and sharing the resulting best practices with other educators. After a two-year trial run in New England schools, CAST plans to expand the program nationally. The Consortium, along with the National Center on Accessing the General Curriculum, a CAST-led initiative sponsored by the Office

continued on page 56

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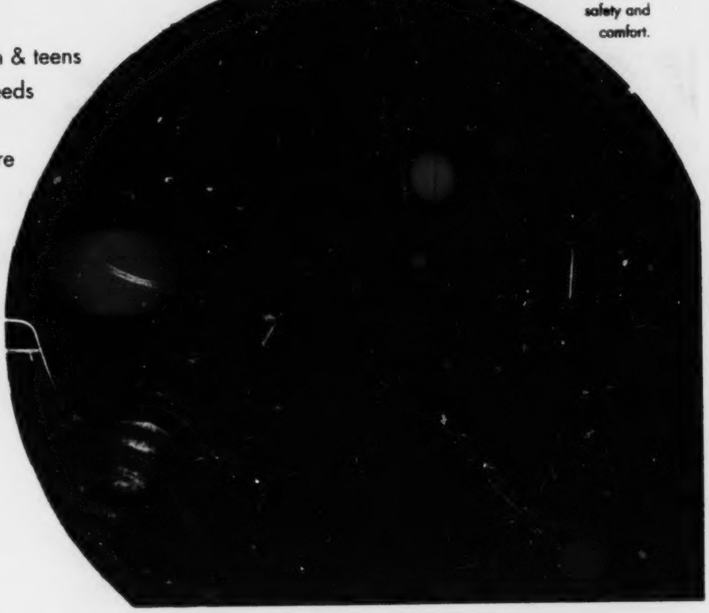

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Circle #93

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of Special Education Programs (OSEP), is working toward the day when all core curriculum is digitized, allowing the kinds of flexibility needed for UDL implementation, and when teachers and students receive ample technological support.

When asked how CAST would determine that Universal Design for Learning was having the sought-after impact in the classroom, Meo came up with the following list as indicators of success:

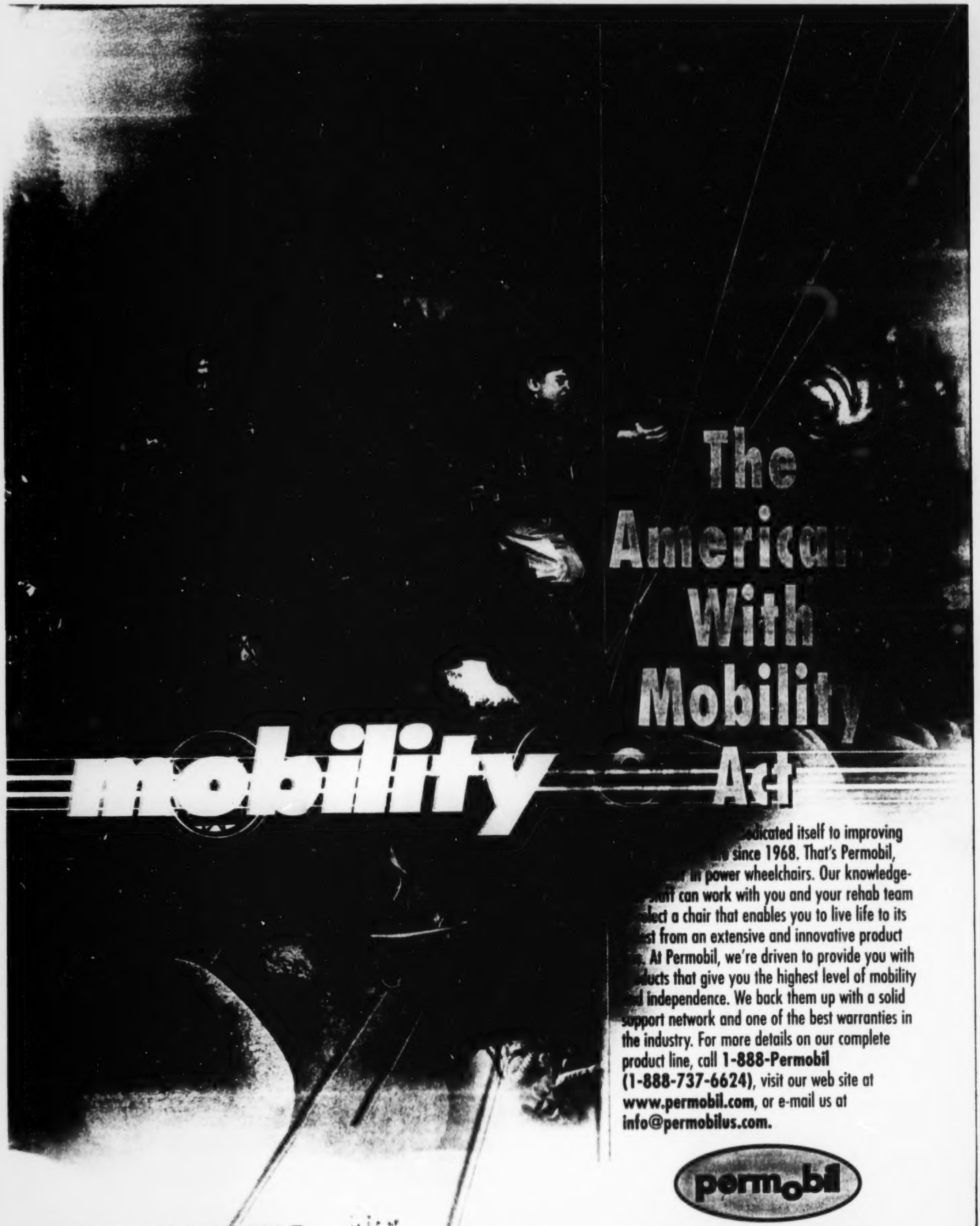
- Higher attendance, fewer behavior problems;
- Special education teachers and regular teachers working side by side;
- Students demonstrate appropriate progress when evaluated;
- Special needs students are provided with full accommodations and alternatives, and find an appropriate level of challenge; and
- Curriculum designers understand how to integrate UDL into materials and classroom practice.

Serving 5,500 students, the Concord, NH public school district is a member of the CAST Consortium and one of a handful of school systems across the country to implement UDL districtwide. Elementary School Special Education Coordinator Donna Palley helps teachers throughout the district to implement the UDL approach in their classrooms. A large part of this effort is the conversion of core curriculum materials to accessible digital format. "The practical aspects can be challenging," admits Palley. "Digitizing materials can be overwhelming for teachers who do it on their own." But Palley is committed to UDL, seeing it as "a very real way to have a significant impact on the development of skills and abilities in all kids." To Palley, the most exciting thing about the approach is how it bridges the gap between regular and special educators. "Unlike some of the other approaches we've tried in special education, UDL is an authentic opportunity for regular and special educators to work together. Regular classroom teachers see the special educators using UDL and want to be part of it. It really breaks down barriers."

At present, the universally designed classroom is still largely a vision for most schools, but with the establishment of the Consortium and the resulting opportunities to conduct further research and to develop new tools and approaches that benefit all students, including those with disabilities, CAST believes this vision is attainable.

Palley, whom CAST recently named the Consortium's first "UDL Fellow," believes parents have the most important role to play in the adoption of UDL by schools throughout the country. "Parents have a huge impact on school change, and a huge responsibility and an opportunity to take this information to their school district and to ask for it to help their child." ■

Lucinda M. O'Neill is a staff writer at CAST, the not-for-profit Center for Applied Special Technology in Peabody, MA. Contact CAST at 39 Cross St., Peabody, MA 01960; Phone: (978) 538-3110; Fax: (978) 531-0192; E-mail: cast@cast.org; Web site: http://www.cast.org.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ANNUAL EDUCATION ISSUE

PARENTS NEED HELP

PREPARING KIDS FOR TEASING

All children, especially those with disabilities, and their parents need to know appropriate ways to minimize the effects of this inevitable part of growing up

The following article is adapted from Sites and Sounds, March 2000, which is published by the Bloorview MacMillan Centre in Ontario, Canada. By way of rehabilitation, education, advocacy and research, the Bloorview MacMillan Centre creates programs and services that help enable children and youth with disabilities and specialized needs achieve their personal best.

While most children in school are teased at one time or another, some research indicates that kids with disabilities are particularly vulnerable. "The reason this is such a hot topic for us is that most often kids are teased about a visible difference," says Bloorview's Melissa Joseph, social worker with our cleft lip and palate and dental services. "So kids with disabilities are at greater risk." In the short term, a child who is teased may experience problems with sleeping and eating, complain of

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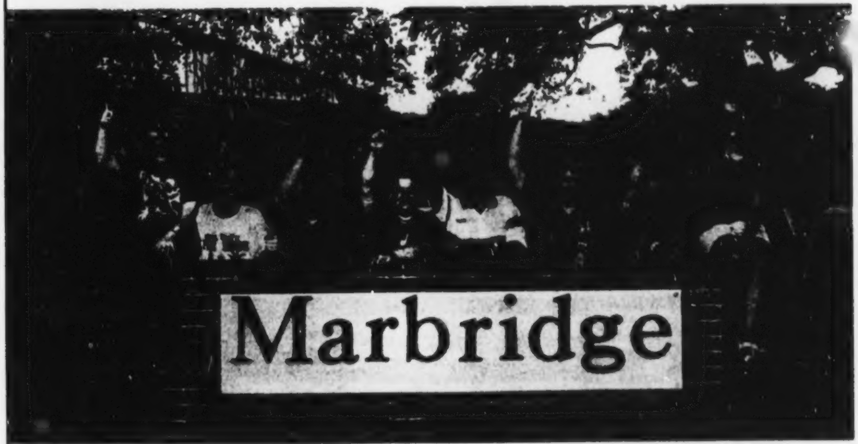

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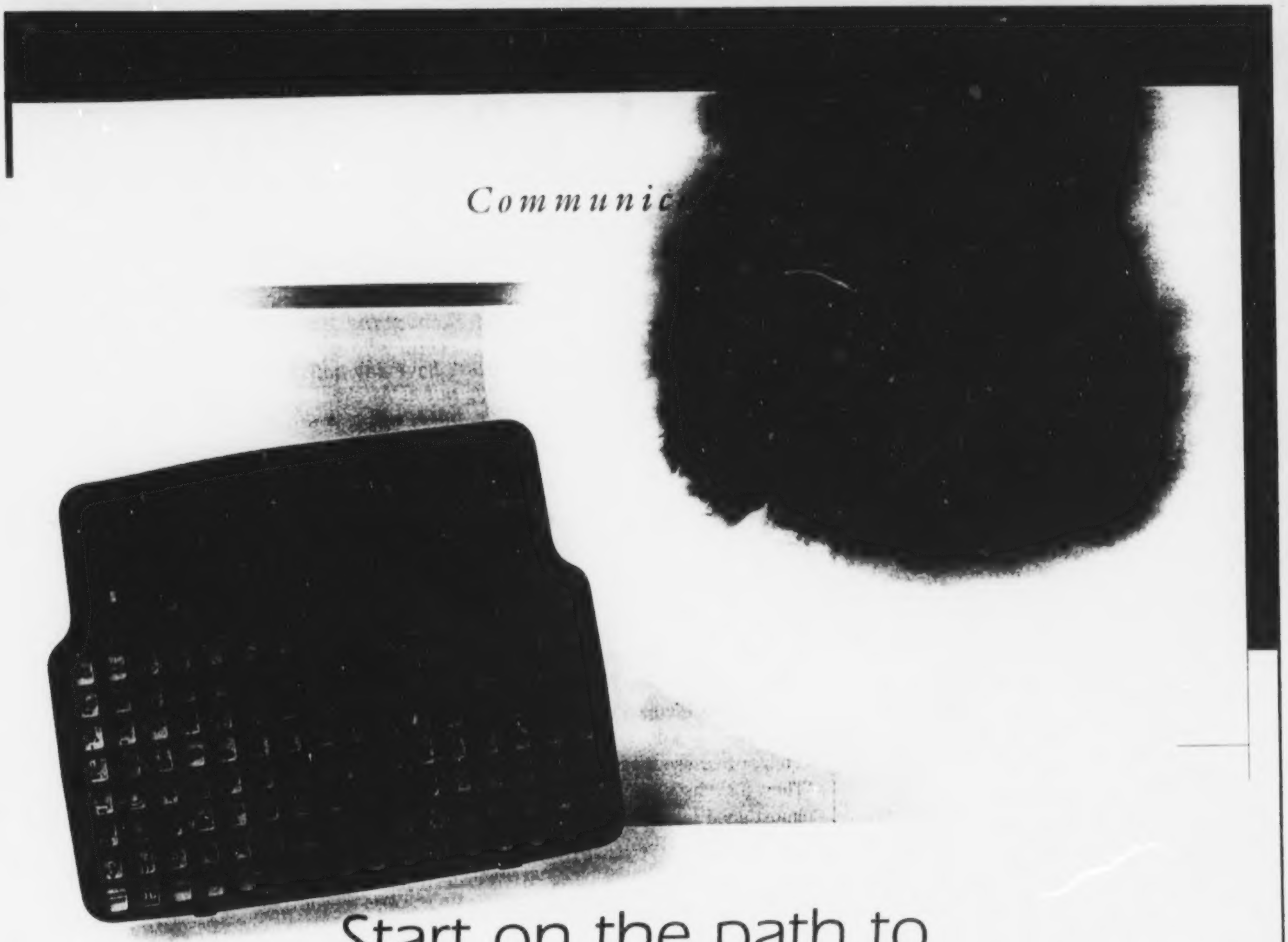

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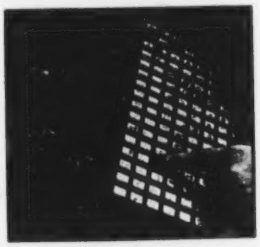

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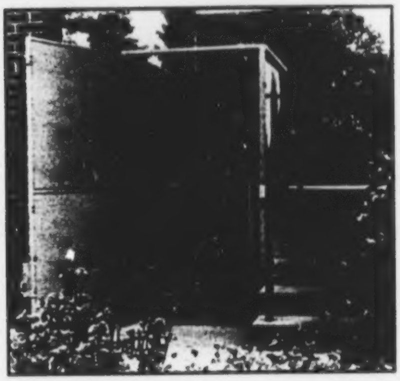

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Clever Comebacks

Children need to practice possible responses to teasing.

BE HONEST
"I don't like what you're doing and I won't stand around listening to it." The teaser, who is looking for a reaction from the child (crying or running away) will be disarmed with this confident response.

EDUCATE THE TEASER
This involves educating the teaser about the disability, but in a positive or humorous way. For example, a child who is teased because he has no hair can say, "You're right, I don't have any hair. I hope it doesn't grow in for a while because I'm going out as Michael Jordan for Halloween." Using humor is highly effective, but is not a skill that comes naturally to all children.

BE DETACHED
A simple, detached response may be more appropriate. For example, "So, what?"; "Your point is?"; or "Tell me when you get to the funny part."

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headaches or other physical pain, or seem withdrawn. Over time, teasing can crush self-esteem and cause depression or other mental health issues. Yet the problem may not be acknowledged by some professionals because they do not know how to help a child, or because they minimize its effects. "They may have the perception that it's almost good for the child, a normal rite of passage," says Barbara Germon, social worker for Bloorview's neurodevelopmental program.

All clinicians should "ask children open-ended questions about how school is going, as well as direct questions about whether they are being teased," continues Ms. Germon. "When teasing is identified, one of our social workers should be involved." While some teasing may be playful, harmful teasing is intended to get a reaction—like fear or anger—and to gain a sense of control over the child. Teasing is most common among children aged six to 12. Professionals and parents have a critical role to play in preparing children with disabilities to handle teasing. "It's human nature to be curious, so from an early age kids with disabilities need to be armed with the information to respond to questions, stares, and unkind comments," Ms. Joseph says. Following are some practical steps parents can take:

- **Educate the child about his or her disability with age-appropriate information.** This means explaining the disability in language the child can understand, and providing concrete examples of what he or she can and cannot do. In social situations, encourage parents to model responses to questions others ask about the disability. This gives the child the words to respond independently in the future.
- **Educate family and friends, as well as parents of children in the child's daycare or school, about the disability.** "Some parents of the child's classmates may feel unequipped to have a child with a disability over to play at their home," comments Ms. Germon. "For example, they may need to be shown how to take the child out of his or her wheelchair."
- **Educate teachers and peers.** Explains Ms. Germon, "School age kids may want to give a presentation." That may include bringing in another child with the same

Encourage children to practice "confident body-language" in front of a mirror. Suggests Ms. Joseph, "Stand up straight, don't back away, speak with confidence, make eye contact."

disability, or having a therapist or parent there for support. "They can describe the disability, talk about how the equipment they use works, and focus on their abilities." Try a game of "Ability Jeopardy" at the end of the session to test kids on what they have learned about the disability in a fun way.

- **Tell parents about disability-awareness/ teasing programs they can bring to their child's school (See box below).**
- **Encourage parents to role-play responses to teasing with their child, even before it happens.**
- **Encourage children to practice "confident body-language" in front of a mirror.** Suggests Ms. Joseph, "Stand up straight, don't back away, speak with confidence, make eye contact."
- **Joining forces with other kids in the class who are being teased can help.** They can group together when one is targeted.
- **Get the child to share ideas with other kids with disabilities.**
- **CAUTION**: If the teasing involves any threat of violence, school officials and staff should be involved, making many of the strategies listed above inappropriate. ■

School programs that help teach disability awareness:

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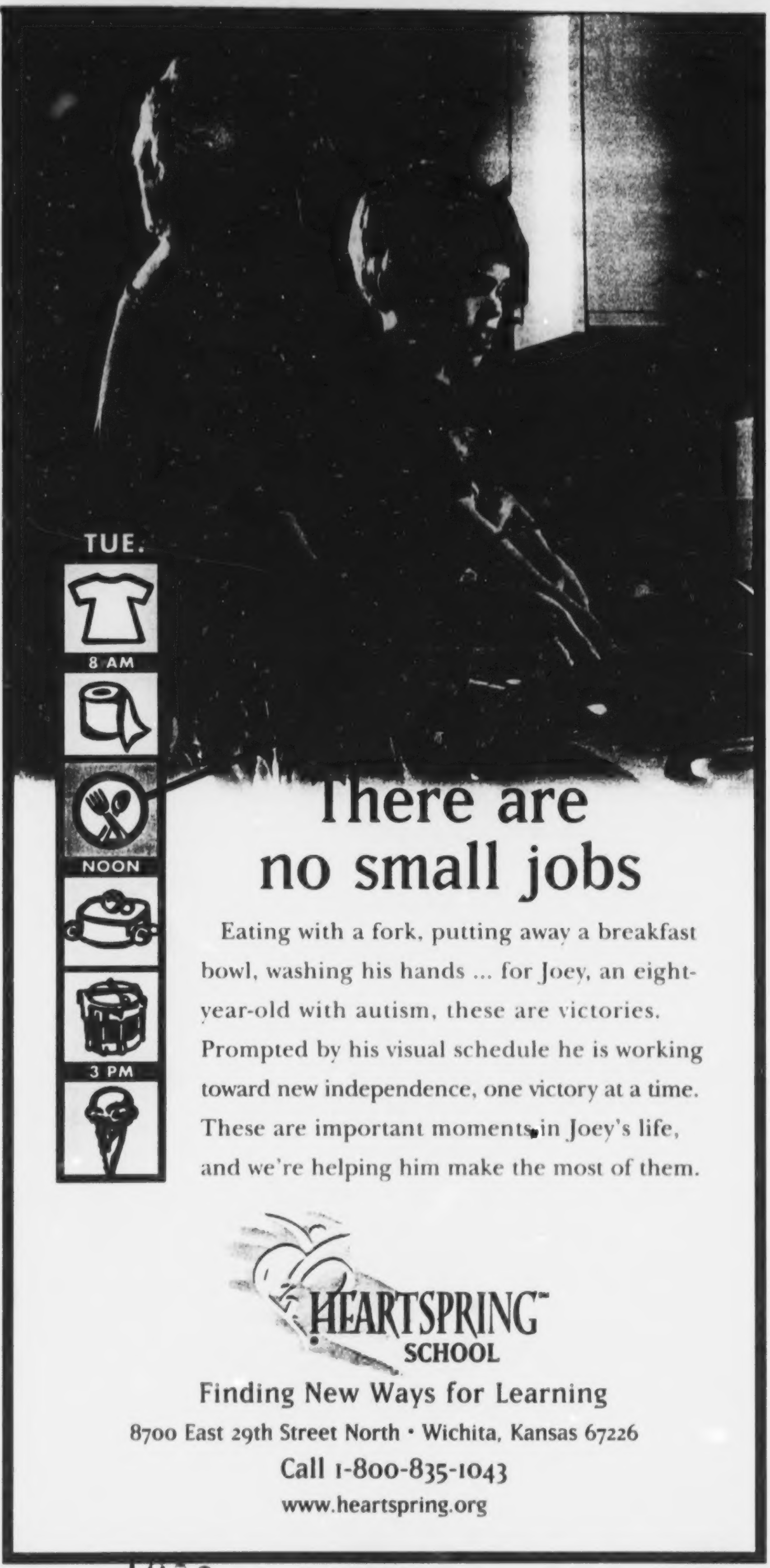

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ANNUAL EDUCATION ISSUE

TEACHING THE TEACHER

About a Child's Unique Health Needs

by Virginia L. Maturen, RN, MSN, MM

As Kathi Orton and I stood on the playground watching our sons play, she remarked, "School isn't even out this year and I'm already worrying about next fall. I wish I had something to give to John's teachers so they could understand his condition. I meet with them each fall to tell them about ectodermal dysplasia (ED), but after a few weeks they seem to forget everything."

I caught the frustration and discouragement in her voice. "Let's do something in writing to re-enforce your verbal efforts," I offered. "Ill help. We'll work on it over the summer."

Understanding ED

Despite being a registered nurse and having worked in community and home care for 25 years, I was unfamiliar with ED. I read the information Kathi gave me and did further research at a nearby medical library. ED is a congenital condition in which the structures of the skin, such as the sweat and sebaceous glands and hair follicles, are absent or malfunctioning.

John Orton has ED. He cannot sweat, has sparse hair, five pointed teeth, and pale, thin skin. Because his body does not perspire when the external temperature is elevated or if John increases his activity level, he is susceptible to an elevation of his core body temperature. His parents' first worry was John's need for an air-conditioned classroom when he started kindergarten. Other problems encountered by people with ED include chronic respiratory tract infections, otitis

> **We agreed that his teachers would benefit from information about ED and each of the problems John could potentially experience during a school day.**

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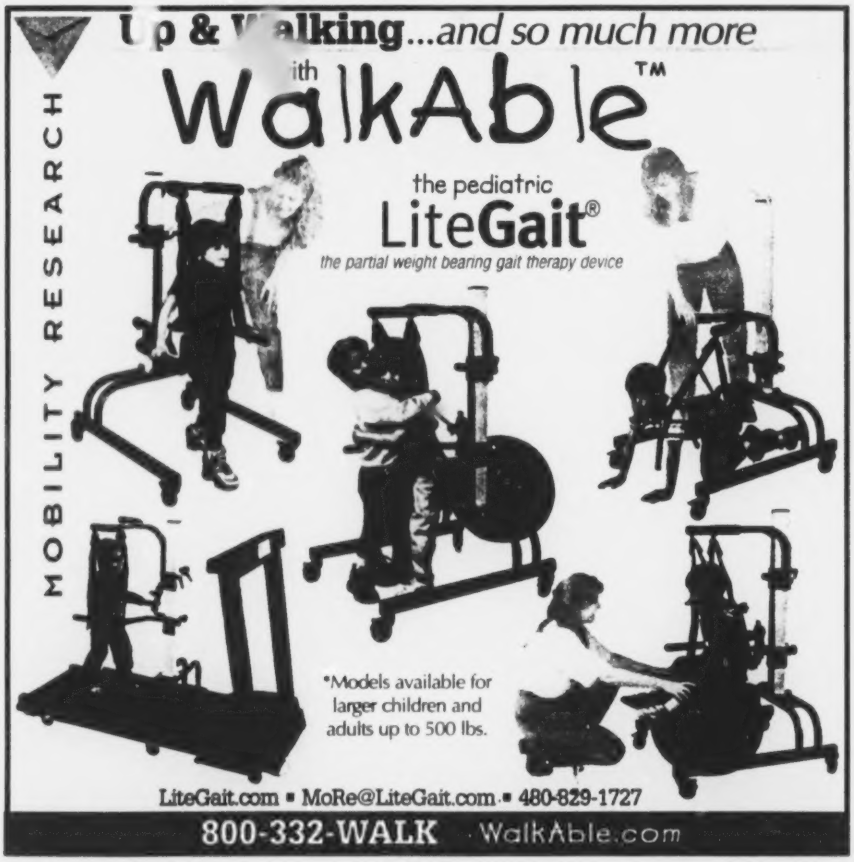

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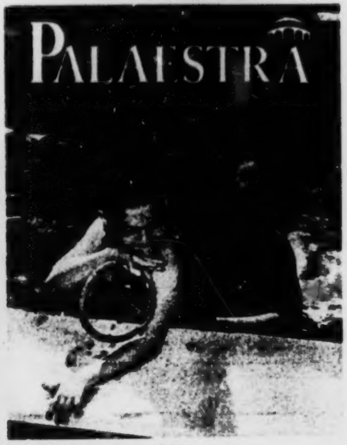

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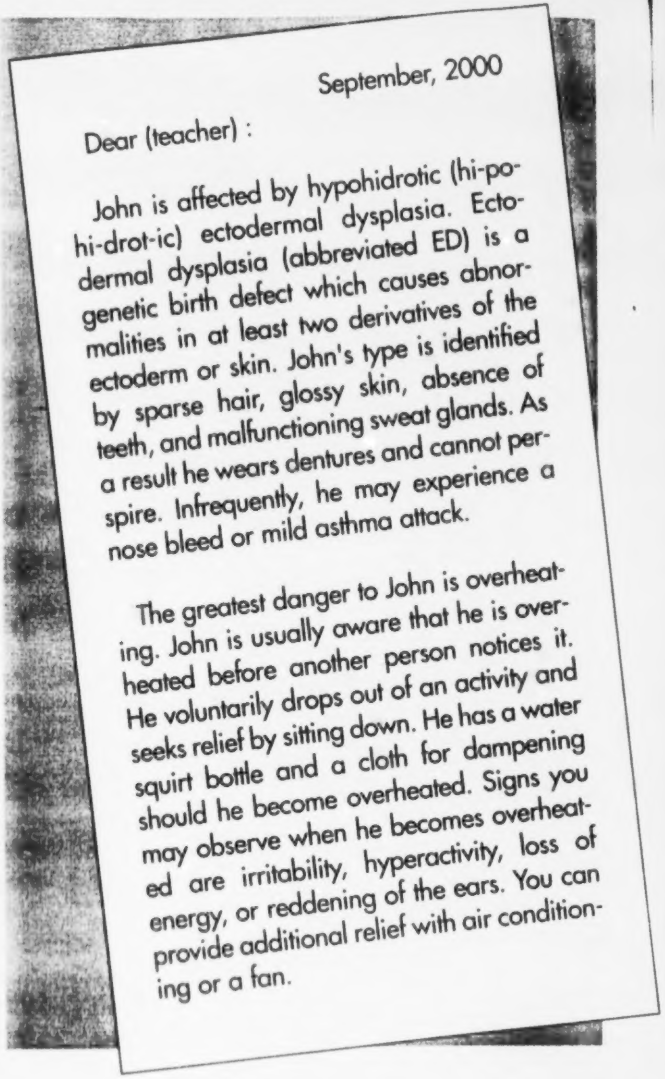

September, 2000

Dear (teacher) :

John is affected by hypohidrotic (hi-po-hi-drot-ic) ectodermal dysplasia. Ectodermal dysplasia (abbreviated ED) is a genetic birth defect which causes abnormalities in at least two derivatives of the ectoderm or skin. John's type is identified by sparse hair, glossy skin, absence of teeth, and malfunctioning sweat glands. As a result he wears dentures and cannot perspire. Infrequently, he may experience a nose bleed or mild asthma attack.

The greatest danger to John is overheating. John is usually aware that he is overheated before another person notices it. He voluntarily drops out of an activity and seeks relief by sitting down. He has a water squirt bottle and a cloth for dampening should he become overheated. Signs you may observe when he becomes overheated are irritability, hyperactivity, loss of energy, or reddening of the ears. You can provide additional relief with air conditioning or a fan.

media, foul-smelling nasal discharge, nosebleeds, asthma, eczema, and dental cavities.

One solution

Having familiarized myself with ED, I questioned Johns mother about his specific problems. We agreed that his teachers would benefit from information about ED and each of the problems John could potentially experience during a school day. Our goal was to prevent the onset of an acute episode causing John to become ill and miss school. Keeping him healthy and feeling good would maximize his learning experience and reduce his absences due to illness.

The problems John experienced in the classroom over the school year included episodes of overheating, asthma, difficulty wearing his dentures, nose bleeds, and eczema. Using an outline

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format, I defined each problem and identified their signs and symptoms, prevention, and treatment strategies.

After the key points for each problem were identified, the information was written as an open letter to John's teachers. (A portion of the letter is shown on the previous page.)

A copy of the one-page letter was given to John's classroom teacher in addition to his gym, art, computer, and foreign language teachers. Personnel in the lunch room, library, and school office also received a copy. The initial feedback was so encouraging that Kathi gave the information to John's baseball and basketball coaches and his Sunday school teacher. At Thanksgiving, she gave the information to seldom-seen family members living in another state. Later she remarked, "Finally, my family understands about ED."

John Orton, of Chicago IL, age 12 has estodermal dysplasia. He is looking forward to entering the seventh grade this fall.

"Write"-on! The letter is a success

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The letter for a child with ED can also be adapted to meet the

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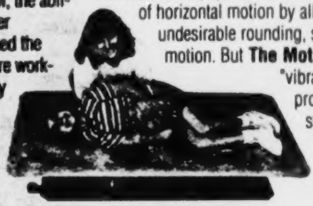

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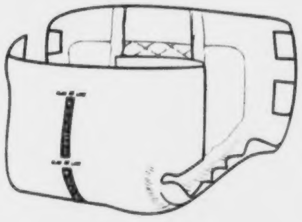

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Circle #54

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informational needs of other children with congenital or chronic diseases or disorders. Communicating information about a child's health needs to school personnel is crucial, but can be very helpful in many other settings as well. Using an outline to assemble relevant information is a good way to get started and helps to organize the essential points. Drafting a letter is the next step and can be a friendly, informative approach to the child's teachers, coaches, scout master, sitter, and other parents who have periodic contact with a child with unique health needs. ■

The letter for a child with ED can also be adapted to meet the informational needs of other children with congenital or chronic diseases or disorders.

Virginia L. Maturen, RN, MSN, MM, is a school nurse in the Chicago, IL, area as well as an individual consultant who develops educational resources and programs for disease mangagement, prevention, and healthy living for children and adults with chronic disease.

For more information about ED, contact:

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Report Addresses Problems in Special Education

Research involving professionals and parents pinpoints areas for action to ensure quality education for children with disabilities

by The Council for Exceptional Children

The following is an overview of the the special report prepared by The Council for Exceptional Children, a professional organization representing special education professionals with the mission of improving education for children who have disabilities and those who are gifted. The group's research results are important for parents as well as educators to know about in order to be informed of the developments in the field and ensure that their child is receiving the best possible education.

—The Editors

Current special education teaching conditions have pushed the field into crisis, with students with disabilities sometimes receiving less than adequate instruction and special education teachers leaving the profession in record numbers, according to a new report by the Council for Exceptional Children (CEC). The report shows that the problem rests not with the special education teachers but with a system that requires them to complete overwhelming amounts of paperwork and carry high caseloads, among other problems, all with too little support. Under these conditions, special education teachers cannot do the one thing they want to do—give their students the best instruction and the best of their time and talents. In fact, 68 percent of special education teachers report that they spend less than two hours per week in individual instruction with each of their students!

The report *Bright Futures for Exceptional Learners: An Action Agenda to Achieve Quality Conditions for Teaching and Learning* recognizes that the problem is prohibitive and will take the collaboration of all to redress. It calls on schools, districts, states, administrators, businesses, federal agencies, professional associations, parents, and teachers to take action and recommend steps each can take to give exceptional children a future bright with promise and opportunity.

In the best of circumstances, successfully teaching individuals with disabilities is exceedingly tough work, says the report. Students with disabilities often cannot achieve unless they are taught by the very best teachers using the very best interventions under the very best conditions. When these conditions are absent, we increase the difficulty of the learning experience for students with special needs, and we may set them up for failure now and in the future.

The report is the work of CEC's Presidential Commission on the Conditions of Special Education Teaching and Learning. Past CEC President Linda Marsal established the commission during her presidency in 1998, and the Delegate Assembly passed a resolution embracing the study that same year. The commission was led by co-chairs Don Deshler, director of the Center for Research and Learning at the University of Kansas, and Matty Rodriguez-Walling, teacher/trainer in the Miami-Dade County Public Schools' Division of Exceptional Student Education.

The commission bases the report on two years of intensive research and fieldwork. Data were collected from hundreds of special and general educators, administrators, and parents, as well as national databases and published research studies. In addition, thousands of professionals participated in forums held in the US and Canada as well as through responses to questionnaires posted on the CEC Web site.

CEC believes the report is the first step to improving special education teaching conditions for teachers and students. In addition to the action agenda outlined in the report,

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CEC is developing special strategies the organization will implement to ensure special education teachers can work under conditions that are conducive to quality instruction and learning.

THE CONDITIONS

The report identifies nine major conditions that prevent special education teachers from presenting effective, high quality instruction. They are:

• Overwhelming paperwork

Paperwork ranked as the number-one barrier to teaching. While special education teachers recognized the importance of Individualized Education Programs (IEPs), they said too often procedural compliance is stressed over thoughtful decision-making, and the amount of clerical work IEPs require is prohibitive. In addition, special education teachers are inundated with other paperwork duties, including completing central office forms, letters and notifications, medical assistance billing records, telephone logs, child abuse reports, due-process documentation, daily/weekly parent reports, discipline records, progress reports, and more.

• High caseloads

Special education teachers also cited high caseloads as a critical concern. In addition to the fact that special education teachers may be assigned a large number of students, which makes it nearly impossible to individualize and provide quality instruction, a teacher's caseload may not take into account each child's disability and needs. High caseloads further encroach on the special education teacher's ability to provide quality instruction, because time to collaborate with their students' general education teachers often is not provided.

• Inadequate administrative and district support

Many times special educators lack appropriate resources for their students, administrative support, and/or professional development opportunities. Too often, special education classes do not receive computers, instructional materials, or other resources. Additionally, administrators may not have the knowledge, skills, or time to support services for exceptional children.

• Ambiguous and competing responsibilities

In the past few years, the role of the special educator has become fragmented and overwhelming. Special education teachers are expected to be teachers, consultants, collaborators, supervisors, counselors, and clerical personnel. As neither schools nor the profession defines the special education teacher's primary responsibility, they are expected to meet the often conflicting expectations of multiple parties: students, administrators, parents, other educators, and the public.

• Isolation

In many situations, special education teachers are still considered "outside" the mainstream. In addition, they are given few opportunities to collaborate with general or other special educators. The result is a sense of isolation and powerlessness to effect change.

• Fragmented licensing systems

Because licensure requirements vary among states and provinces, dedicated and qualified special education teachers are often unable to find jobs. This contributes to the high attrition rate of special education teachers and leaves students who need the services of these individuals without teachers who can do the most for them.

• Poorly prepared new special and general educators

Many new special and general education teachers are finding they have been prepared for jobs that no longer exist and that they are ill-equipped for the jobs they face. The result is poor instruction and a high attrition rate.

• Increased demand for well-qualified special educators

The need for qualified special education teachers is an ongoing problem that is not abating. Recent data show that in the US more than 30,000 teachers without appropriate licenses teach students with disabilities, and in some urban and rural schools, close to half of the teachers are unqualified.

• Insufficient focus on student outcomes

Special education teachers are forced to spend too much of their time on activities that do not contribute to their students' educational success. Not only is this frustrating for our teachers, it directly impacts the quality of educational services students with disabilities receive.

THE ACTION AGENDA

Though the goal is daunting, we can change current special education teaching conditions. It will take the collaborative effort of teachers, administrators, districts, states/provinces, business, federal agencies, and teacher education programs. If these "Partners for Action" join together for effective change, we can ensure that:

- Every exceptional child receives individualized services and supports from caring and competent professional educators.
- Every special and general educator has the teaching and learning conditions to practice effectively.
- Every instructional leader establishes strong expectations for the use of effective and validated instructional practices.

CEC recommends the following action agenda as a beginning in these essential changes:

• Provide technology and clerical supports to reduce the paperwork burden

Schools must provide teachers with the technology they need for electronic case management, communication, record-keeping, data analysis, and ongoing instructional modifications and accommodations. Also, by providing personnel for clerical tasks such as preparing due-process notices, completing district forms, and tracking re-evaluation timelines, the special education teacher can focus on teaching and learning.

• Standardize decision-making processes

Districts/boards, schools, and teachers should be able to use a universal set of processes to document effective and complete assessments, program planning, and student progress. Special educators should have standard tools to document these processes.

• Define the role of special educators

Schools and districts should define the role of special education teachers. Central and building-level administrators should work with special educators to redesign and make explicit special educator responsibilities.

Special education teachers bring expertise in providing intensive and focused instruction and in developing instructional strategies to meet the individual needs of students with disabilities. They also know how to make accommodations or modify the general education curriculum for students with special needs. Schools should ensure that special educators use their skills and knowledge for the best educational results for exceptional children.

• Provide supports for special education teachers

CEC and school districts can support special educators in many ways:

- CEC, with the Partners for Action, should develop caseload guidelines.
- Teachers who document their accomplishments against recognized standards should qualify for salary incentives.
- District/board and school administrators who understand the responsibilities of special education teachers should collaborate with and support their special educators.
- Ongoing assessment data about the conditions of teaching within school districts and boards should be used for continuous improvement at the local level.

• Create a career continuum in special education

Teacher preparation programs must ensure that special education teacher candidates have a breadth of experiences in school settings that prepare them for the daily challenges they will face. Also, teacher preparation programs and school systems must increase the opportunities for ongoing professional development for special education teachers and create a career ladder for accomplished teachers who mentor their colleagues.

• Create the context for high-quality practice

All professional development programs, including those for pre-service and experienced special education teachers, must meet three standards:

- The content should emphasize research- and experience-validated instructional strategies that have been proven to be effective for exceptional children.
- The curriculum should provide teachers with sufficient detail, examples, demonstrations, and practice so that they can use the new instructional practice proficiently.
- The curriculum should be based on adult learning principles such as providing educators a voice in designing professional development experiences, modeling, and peer coaching. Also, learning to teach must include more extensive experiences in classrooms earlier and more consistently.

• Develop cohesive licensure systems

Licensure requirements for special education teachers for each state and province should be standardized, which would allow

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Circle #83

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teachers to apply for jobs where the jobs are. Also, special education preparation programs should align themselves with CEC's validated professional standards.

- **Recruit and prepare sufficient qualified diverse special educators to meet demand**

A coordinated recruitment campaign for special education teachers must be implemented. The campaign should target secondary students as well as career changers, and programs that prepare special education teachers must have the capacity to prepare sufficient numbers of qualified diverse special educators.

Some beginning suggestions for parents:

- Ensure that your child receives services from fully licensed and qualified personnel.
- Support initiatives in your area to recruit and retain the best and brightest special educators.
- Work to ensure that the adults in your child's school reflect the diversity of the larger community and nation.
- Work with your school and district to get teachers appropriate working conditions.
- Ask about the research that supports the interventions in your child's IEP and how the school ensures they use proven strategies.
- Insist that the special educators in your area have reasonable caseloads and class sizes.

For a copy of Bright Futures for Exceptional Learners: An Action Agenda to Achieve Quality Conditions for Teaching and Learning, contact the CEC (see below). A more-detailed summary of the report is in the July/August 2000 issue of TEACHING Exceptional Children. ■

The Council for Exceptional Children (CEC)

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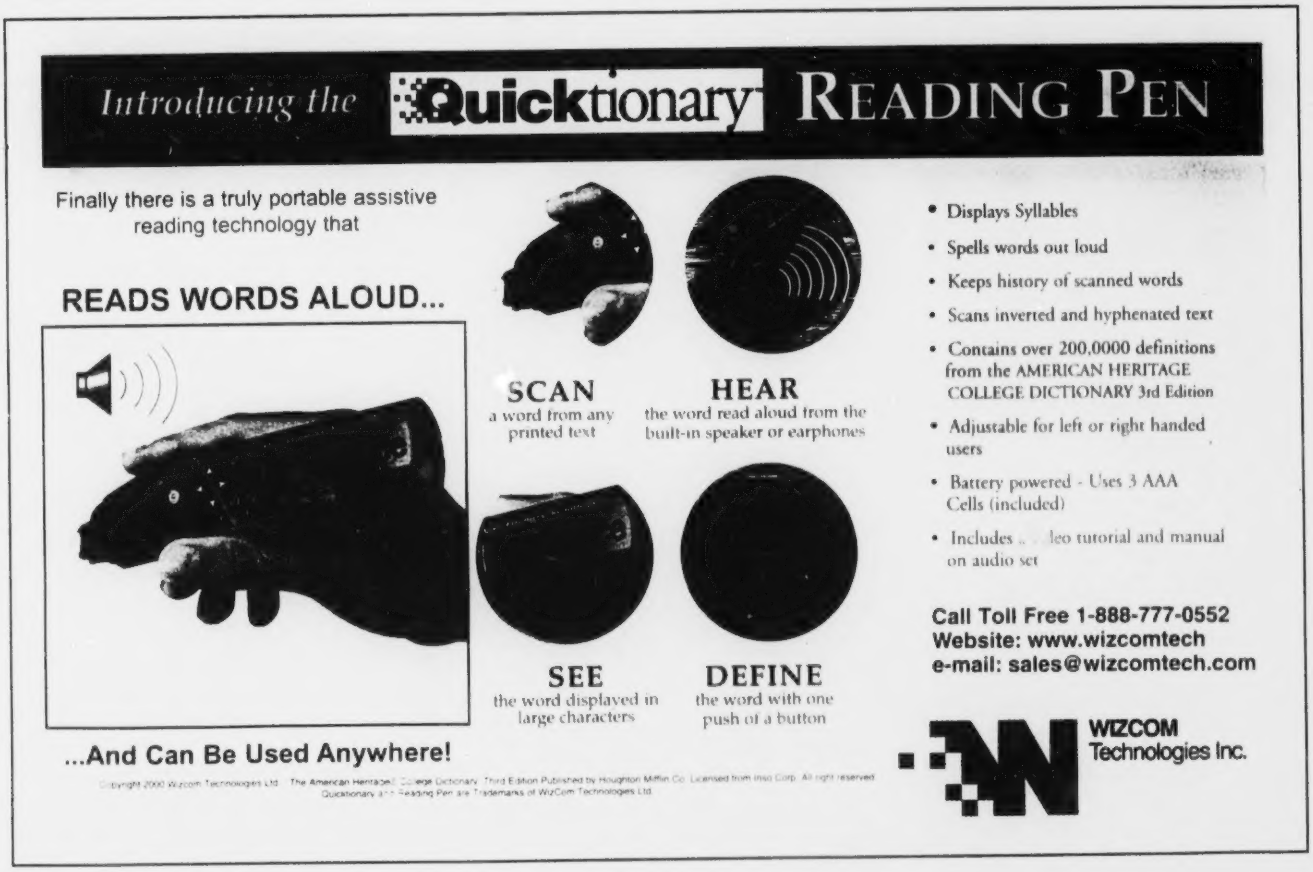
The Council for Exceptional Children (CEC) is the largest international professional organization dedicated to improving educational outcomes for individuals with exceptionalities, students with disabilities, and/or the gifted. CEC advocates for appropriate governmental policies, sets professional standards, provides continual professional development, advocates for newly and historically underserved individuals with exceptionalities, and helps professionals obtain conditions and resources necessary for effective professional practice.



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Circle #103

When Different Is the Same

Including a child with a disability in the regular classroom environment can be challenging, yet ultimately, rewarding

by Jodi Buchan

ANNUAL EDUCATION ISSUE

If you saw my 14-year-old daughter Katie enter the middle school lunchroom you would notice that she bobs the top half of her body a little to one side to gain momentum. You would hear Katie's open-mouth hums and Peter Pan-like "crows" join the cafeteria chaos followed by, "Hi, Katie" from several of her schoolmates.

Included from the start

Katie has been in inclusive environments since she was an infant. We lived in a small Rocky Mountain resort community where large city "segregated" programs were unavailable: Katie was "included" as another member of the community in daycare and school services.

Katie was in daycare right alongside the babies who sat up and crawled, though she remained stationary. When she was not in daycare I took her for private therapy, as therapy in "natural environments" had not yet evolved.

When Katie started kindergarten, the transportation director installed a seat belt with a harness so she could ride the big yellow school bus with the rest of the neighborhood children. Each morning the children greeted her, and some even volunteered to sit beside her. However, one blue-eyed boy with rebellious strands of blond hair use to customize his greeting each morning.

"Hi, slobber mouth," he would say, always careful to give his friends a glance before chuckling his way to a seat in the back. Katie would respond with her usual glistening grin, enjoying the laughter.

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Katie, 14, has been in inclusive environments since infancy.

Just one of the kids, Katie enjoys swimming with her classmates.

Katie always has volunteer peer-aid helpers eager to assist her in class.

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Time changes attitudes

That was at the beginning of the school year. By spring, I noticed a metamorphosis: this bully turned into a peer. He was reading books to Katie in library period and bringing her pictures he made in art marked "TO KATIE" in crayon. The teachers said while he was discrete about his goodwill, he also stopped making fun of her.

That was also the year Katie used a special wooden chair on wheels with a tray clipped to the front for eating and fine motor skills. The chair helped her support the trunk of her body. The children in the school nicknamed Katie's chair "the Ferrari," and would run up alongside it in the hallways like a devoted pit crew, their backpacks bouncing in unison.

Dealing with doubts

Later in the school year Katie's teacher said, "Let's put Katie in the Christmas music production." At first I was pleased to have her included in the festivities, but eventually reality became painful to watch. She would sit or stand when physically prompted by a teacher or an older schoolmate. The spotlight would shine on the children as they waved their hands like pine boughs and sang "Jingle Bells." But the bright beam of light seemed to magnify the contrast of Katie's lack of focus and participation. People would say to me, "It's great to see Katie up there." I just blinked back tears, swallowed the lump in my throat, and quit trying to include her in extracurricular activities.

Rather than the typical fifth-grade curriculum of Math, Geography, and English, Katie's individual education plan (IEP) included self-help skills like feeding herself, dressing herself, and learning to use the toilet. I wondered if she really belonged, if her experience was one-sided, if she contributed to the class.

When I discussed this with her teachers they told me how good it is for the rest of the kids to have Katie in school with them. "It's good for their self-esteem," they said. "Katie always has lots of classmates volunteering to help her, to read to her, or to do the cooking projects with her." It seems to me like inclusive education naturally promotes what the national movement in schools proposes to teach: universal values.

As I walked through the school hallway one day, a boy said something to me as I passed. "Katie's a lot easier once you get to know her," he commented, not quite looking at me. Initially, I was surprised an 11-year-old boy would strike up a conversation with someone's mother. Then I realized that he felt he "knew" Katie. "Oh you know Katie?" I asked. He is still walking, but he does a half turn into a backward stride to face me. "Yeah," he said, casually pleased. "I'm in cooking class with her." I grinned.

Adjusting to meet the future

I have learned to look past the loss of "normal," grin through the grief, and notice the way children are with Katie. I see it in her smile, when she does a little circle dance around the driveway as the bus comes to pick her up and when I visit the classrooms.

Each fall as I go to Katie's class and talk about Katie, I try to answer their questions—try to eliminate some of the fear-of-the-different factor. "What happened to her?" they ask. "Does Katie have any pets? If she can't talk, can she hear?"

I tell them a little about Katie, how she can hear you say "hello" but she cannot say "hi" back. I tell them that she was born with a "hurt" brain. "Doctors gave her lots of tests," I always say. "But she is undiagnosed. We don't know what happened or how she'll be when she grows up." I tell them incoming messages get scrambled, or have to take detours around the "hurt" parts and sometimes gets lost.

When Katie reached fifth grade, we played the same "Fun Game." I start the game by asking the class, "What about Katie is the same as you?" A few children raise their hands.

"She likes to swim," volunteered one little girl.

"She likes horses" said another.

"She dresses the same!"

Suddenly hands were clamoring faster than a recess bell stampede. Then a boy with thick brown hair, who sits across the aisle from Katie and her sometimes-vacant desk, raised his hand. "She's a human being," he said.

I guess different really is the same. ■

Jodi Buchan is the mother of Katie as well as NW Regional Health Care Program for Children with Special Needs (HCP) Family Advocate and Routt County, Part C Coordinator. She, her husband Glenn, and Katie make their home in Steamboat Springs, CO.

Katie and her friends go sledding.

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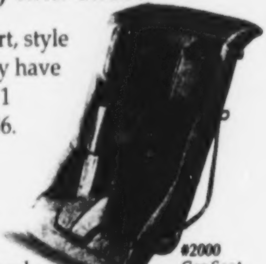
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ANNUAL EDUCATION ISSUE

THE IEP MEETING

All Together Now...?

By Judy Bordin, PhD, and Rebecca K. Lytle, PhD

Have you ever attended an Individual Education Plan (IEP) meeting and experienced the following:

- When you walk in, everyone is talking and no one looks at you?
- The professionals tell you their names and their titles in alphabet soup?
- They hand you assessment reports in rapid fire?
- No one seems to realize how scared or nervous you may be?
- No one asks about your family or how your child might be at home?
- Everyone speaks in jargon?

The Individuals with Disabilities Education Act (IDEA), the legislation serving students with special needs and their parents, clearly points to a "team" concept in IEP preparation. The intent of the law, we believe, is to allow parents and professionals the opportunity to engage in meaningful conversations about the needs of the child. All are to have input into the development of a plan to guide the child's education. In other words, they are to function as a team. There are a variety of factors that should be present within a team. They include: social support, proximity, distinctiveness, fairness, similiarity, and communication. The following checklist is an informal way for you to evaluate your IEP team atmosphere. Answer the following questions with a "yes" or "no." Score 1 point for each "yes" and 0 points for a "no."

CHECKLIST

Social Support: An atmosphere where people can share and be offered understanding, compassion and encouragement.

1. Does your school have a parent support group for parents of special needs children?
2. Do your meetings start with a list of your child's strengths?
3. Has the district informed you that you may bring anyone you like to your IEP meeting for support?
4. Has your district given you information about the local family resource center?

Social Support Total________

Proximity: The more time that people spend with each other, the more likely they are to develop a relationship.

5. Has the school invited you to observe or volunteer in your child's class?
6. Have you received positive comments from your child's teacher either in person, by phone or E-mail?
7. Do the team members at the IEP meeting stay focused on your child?
8. Has the school invited you to watch the therapy or other services that your child receives?

Promixity Total ________

Distinctiveness: A sense of unity or purpose.

9. Have you shared information about your child's home life in writing or with photographs?
10. Have you presented past reports from other sources (e.g., doctors)?
11. Have the teachers shared their goals for your child before the meeting?
12. Do the school personnel seem to really "know" your child?

Distinctiveness Total__________

Fairness: The ability to work together for the child in a spirit of camaraderie.

13. During the IEP meeting, do you feel free to stop and ask for clarification or for a definition of a word or phrase?
14. Do you feel as if your concerns are being considered?
15. Has your school provided you with information about the IEP process?
16. Have you received the results of your child's assessment tests before the meeting?

Fairness Total______

Similarity: Sharing things in common with each other.

17. Do you feel like you and others on the IEP team are all working toward a common goal?
18. Do you feel as though you are listened to when discussing your child?
19. Do you think your information is seen as valuable to the other team members?
20. Do you feel like you are familiar with the curriculum and goals for your child ?

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continued on page 76

1013

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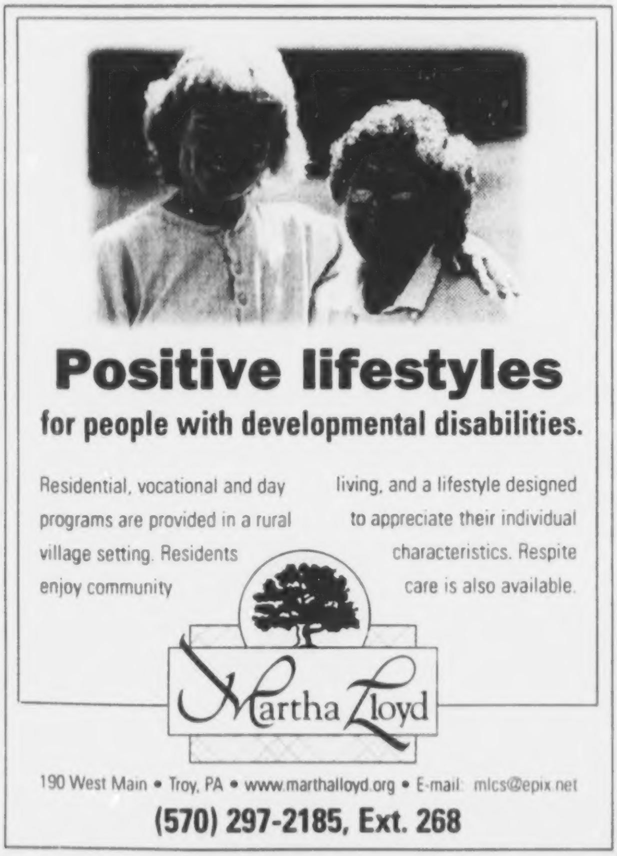
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Martha Lloyd

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Circle #70

continued from page 74

CHECKLIST

Similarity Total____

Communication: The process of sharing information, ideas, and feelings in three different ways. These forms are written, verbal, and nonverbal.

21. Have you been given notice 10 days prior to the IEP meeting?
22. Have you given written permission for your child to be assessed?
23. Have you been given a copy of your legal rights as a parent?
24. Are you receiving information about your child's progress at the same intervals as the general education program (i.e., when report cards come out)?
25. Are controversial issues discussed prior to the meeting so there are no surprises?
26. Does the individual who facilitates your IEP meetings allow everyone to talk?
27. Is the atmosphere of the IEP meeting friendly and supportive?
28. Did you make a list of any questions you have and bring copies of it to share at the meeting?
29. Does everyone seem focused on the matter(s) at hand?
30. Is there a sense that all participants want to work together to meet your child's needs?

How did your IEP team do?

Total each of the following section scores

Social Support (out of four points)____________________

Proximity (out of four points)____________________

Distinctiveness (out of four points)____________________

Fairness (out of four points)____________________

Similarity (out of four points)____________________

Communication (out of ten points)____________________

GRAND TOTAL____________________

24-30	**awesome team cohesion**
18-23	**somewhat cohesive team**
12-17	**can work on cohesive team strategies**
below 12	**reevaluate the team process**

If your team scored 18-30 points they are doing quite well. If your team scored less than 18 points you might want to look at the areas where your team scored poorly and consider sharing this information with the team. Working as an effective team is not an easy process, but it is one that should not be overlooked, as it is imperative for the benefit of the child. ■

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Issues Critical to Parents

Some key points from the Individuals with Disabilities Education Act Amendments of 1997 (Public Law 105-17)

- Parent participation is mandated in initial eligibility and placement decisions.
- Voluntary mediation is set forth as a means of resolving parent-school controversies.
- Modifications and accommodations must be made when children participate in IEPs.
- Before a child can be reevaluated, parents can participate in a review of the data and must provide informed consent.
- Parents help make all eligibility decisions.
- IEPs must include statements of how parents will be regularly informed of their child's progress toward IEP goals.
- The IEP team must review existing evaluative data provided by the parents.

Judy Bordin, PhD, is an Associate Professor of Child Development at California State University, Chico. She has experience working with families in Head Start and other parent education agencies and consulting with state community care licensing agencies. She is the mother of two grown children. Rebecca K. Lytle, PhD has been the coordinator for the Adapted Physical Education Program at California State University, Chico, for the past six years. In addition, she taught adapted physical education in the public schools of rural northern California for 10 years, and is the mother of two children, ages 5 and 7.

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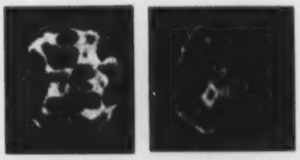

(Red indicates improvement)

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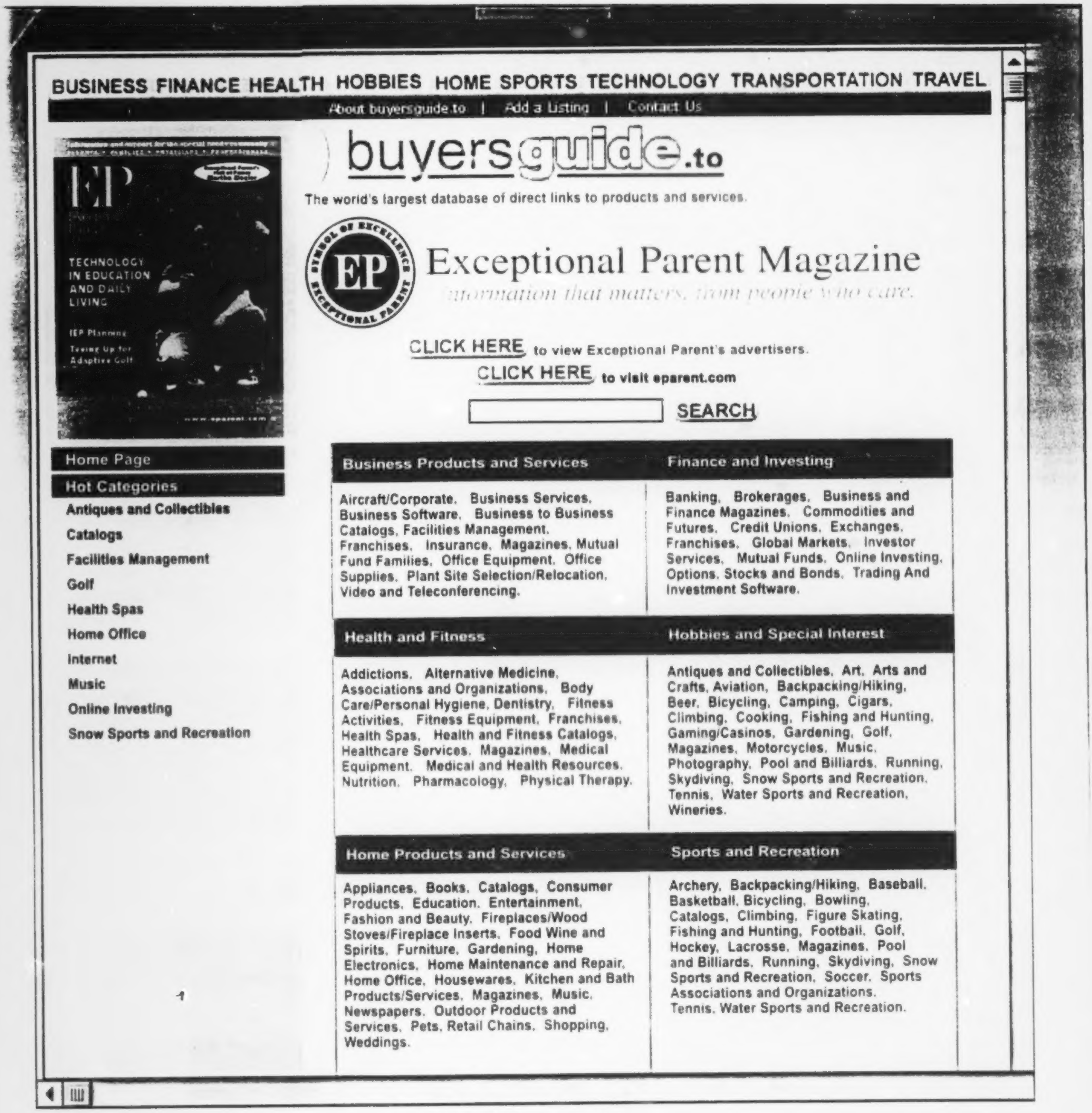
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Circle #21

HLHS Picnic

"Little Hearts," BIG DREAMS

by David Chamalian

Little Hearts' June 4, 2000, annual picnic. All the children shown here were born with Hypoplastic Left Heart Syndrome (HLHS)

What do Farmington, Connecticut, lots of food and a host of activities, and most important, 95 families with kids with special needs have in common? They were all part of the annual picnic gathering organized by Little Hearts, a New England-based support network for families of children with congenital heart defects (CHD).

The picnic is planned each year as an informal event in a relaxed setting (this year's picnic, the fourth annual, was held at a summer/ski resort), where parents can bond and exchange advice and ideas on caring for their children. Meanwhile, the kids keep themselves busy with the various activities and do their own bonding among new and "old" peers who also have CHD. Since the first Little Hearts' gathering was held four years ago, the picnic has grown nearly ten-fold in participation.

Lenore Cameron, the organization's founder, applauds the growing awareness of children born with CHD, especially since her son was born four years ago with a particularly serious form called hypoplastic left heart syndrome (HLHS is a condition characterized by an underdeveloped left side of the heart. In people with HLHS, the heart is incapable of pumping enough blood to the rest of the body, and most important, to the other vital organs. HLHS affects approximately

continued on page 82

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Circle #23

continued from page 80

1 in 8,000 children born in the United States). However, she recalls the agony of first hearing her son's diagnosis and having to quickly choose among only three options available to a parent whose child is born with HLHS: 1) a heart transplant, which requires waiting for an available heart, and once found, bears the uncertainty of rejection by the body of the recipient; 2) "comfort care," which means no medical intervention and allowing the infant to die naturally; and 3) the Norwood Procedure, a proven-successful surgical option involving a series of three surgeries that can rebuild a congenitally damaged heart—ultimately, the option she and her family chose for her son.

Unfortunately, according to Ms. Cameron, even twenty years after the first Norwood procedure was done, HLHS is still viewed by healthcare professionals as a "death sentence," and little hope, even with the promise of the Norwood procedure, is given to parents by medical staff who counsel them. The Cameron's found someone willing to help, however. "Within minutes after speaking with the cardiothoracic surgeon-in-chief, we changed our minds. Jeffrey [our son] had his first surgery at 18-days-old and came home almost three weeks following his first surgery." Today, according to Ms. Cameron, Jeffrey is a "heart-healthy seven-year-old." ■

Next year's fifth-annual picnic will be held on Sunday, June 3, 2001. Anyone interested in participating can contact: Lenore Cameron, 1 Springdale Rd., Cromwell, CT 06416; Phone: (860) 635-3222; Email: LENORE1231@aol.com; Web site: www.littlehearts.net.

Where Are They Now?

FEBRUARY '98 COVER STORY: ANTHONY PIETRI

For an average kindergartener, life normally presents few problems. For Anthony Pietri, who turned 6 in May, life has been a series of grave challenges.

Just days after his birth, Anthony was diagnosed with HLHS. Having decided not to wait for a heart transplant, Dominick and Rose Pietri, Anthony's parents, opted for the only other hope at saving their son's life, the Norwood Procedure. In a recent "where-are-they-now?" interview with Mr. Pietri, EP has learned that Anthony is now living life like any other kid his age. "Anthony's just an everyday kid who can't wait to get into the first grade," beams his father.

Rocky road to health

Though the Norwood Procedure proved successful for Anthony, EP has learned that there had been some setbacks along the way. Last year, when Anthony was 5-years-old, he began to complain about "not feeling well," and his parents noticed he was often cranky, agitated, and without appetite. A doctor's examination revealed that a part of his atrial septum had begun to grow scar tissue, which obstructed blood flow. Anthony had also developed a condition that, though rare, may occur in some children with HLHS: protein-losing enteropathy (PLE), which is an abnormal loss of protein into the gastrointestinal tract.

Anthony eventually needed heart surgery to correct the atrial septum—making it his fourth heart surgery in his five years—but, according to his father, his recovery has gone smoothly so far, and his PLE condition is under control with medication. Mr. Pietri also adds that his son has been both brave and mature about his illness and surgeries. "He knew very well this time what was going on and made it through like a champ." Anthony's brother, Dominick Salvatore, 12, is also thrilled about the successful recovery of his little brother. According to their father, "they have a great relationship and are best buddies." Nevertheless, Mr. Pietri laments the days when he was compelled to put the well-being of Anthony before that of his healthy son. "In the beginning it was hard because Anthony's well-being was our foremost concern, and as parents we just weren't there [for Dominick Salvatore]. He lost out on a good two years of our parenting." Thanks to the help of a compassionate family and community, however, all turned out well. Looking back, his best advice for those who face a similar situation is to rely on family and friends for support. "A lot of people helped: aunts, parents, friends, or grandparents would watch Dominick Salvatore. It was a joint effort, and they were very understanding."

Currently, Anthony is under no physical-activity restrictions. Except for overly rough-and-tumble sports or play, he is able to participate in almost any activity. "They told us to treat him like a normal kid," says Mr. Pietri, "and that's what we do." Even bumps and bruises pose no medical threat. Like a lot of kids his age, Anthony is active in sports. He loves basketball and, according to his father, "carries the ball around with him all over the place." Though his long-term prognosis is uncertain, Anthony's parents cherish their son's health and are grateful for the opportunity to watch him be just like any other healthy child. "He lives his life to the fullest, and we don't really worry about tomorrow."

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The National Association of State Directors of Special Education

The National Association of State Directors of Special Education (NASDSE) is a professional organization representing the state administrators of education programs for children and youth with disabilities in the 50 states and federal jurisdictions. Members have responsibility for directing, coordinating or supervising programs and services for the education of students with disabilities. NASDSE offers affiliate memberships to all who are interested.

NASDSE's purpose is to provide services to state agencies to facilitate their efforts to maximize educational outcomes for individuals with disabilities. Since its inception, NASDSE has been at the forefront of debate and policy development concerning the education of individuals with disabilities.

A not-for-profit corporation, NASDSE is governed by an eight-member board of directors. The Board provides guidance and direction on NASDSE activities in accordance with policy decisions made by the membership.

NASDSE activities

Based in the Washington, DC, area, the NASDSE staff works closely with the US Department of Education's Office of Special Education Programs (OSEP) sharing feedback from its members on policy issues generated at the federal level. NASDSE's government-relations staff monitors federal, legislative, and regulatory activities in order to keep its members informed of new initiatives that will have an impact on special education programs at the state and local levels.

NASDSE played a major role in the reauthorization of the Individuals with Disabilities Education Act (IDEA) in 1997. Since passage of the reauthorization, which made major changes in the programs covered by the law, NASDSE has worked to provide input into the development of the implementing regulations and other policy statements. NASDSE has served as an intermediary by sharing the concerns of its members and helping to ensure the dissemination of information to members. NASDSE staff also monitors other legislative initiatives, including the annual federal appropriations process, and new legislative initiatives that would provide support to children with disabilities and their families.

NASDSE projects

A variety of projects that generate research, provide professional development opportunities, and disseminate information and materials on current issues to a broad audience of educators, policymakers, and parents are currently underway at NASDSE.

- **The Policymaker Partnership** works with 11 primary partner organizations, eight supporting partners, and 22 linking partners to disseminate information about the IDEA and to infuse special education issues into all areas of state and local decision making. NASDSE also works with the Alliance for Families Project located at the PACER Center to support children with disabilities and their families.
- **Project Forum** facilitates communication between the federal government and state directors of special education, summarizes and distributes national program information in order to improve services provided under IDEA, and analyzes policies and emerging issues of significant national concern.
- **Project SEARCH** is conducting a study of policy related to the education of students with disabilities in charter schools.
- **The Professional Development Leadership Academy** is developing state team models that will create supportive learning systems to promote development, learning, and higher levels of success for all children.
- **The Early Childhood Services Project** provides information and technical assistance to state and local educators who provide supports and services for young children with special needs from birth through five years of age.

- **The Blind Education Initiative** is developing and disseminating an educational-guidelines document for state and local education agencies, parents, and consumer groups.
- **RIATT@NASDSE** disseminates training materials to professionals who work with individuals with disabilities. Assistive and learning technology courses, complete competency strands, and complete distance education courses for CEUs or college credit are offered through the Research Institute for Assistive and Training Technologies (RIATT).

For more information on NASDSE projects, visit our Web site: http://www.nasdse.org

NASDSE information services

NASDSE uses a variety of media to keep its members current on important topics and to assist state education agencies in becoming the focal point for dissemination of data to local education agencies, parents, and educators. These include:

- Satellite conferences for state and local educators;
- "Counterpoint," NASDSE's quarterly newspaper, which is circulated to more than 120,000 state and local policy makers, local special education administrators, parents and special educators;
- Liaison Bulletins, which are periodic bulletins that focus on a single hot topic, such as special populations, resources for special educators, and legal issues related to the 1997 IDEA amendments; and
- NASDSE's Web site—http://www.nasdse.org—which provides information on NASDSE-sponsored activities as well as links to other resources for policy makers, educators, and parents.

NASDSE has an extensive list of publications and tapes available. A description is contained in the current issue of Resources and Information. For a free copy, contact NASDSE at: 1800 Diagonal Rd., Ste. 320, Alexandria, VA 22314; Phone: (703) 519-3800; Fax: (703) 519-3808; E-mail: nasdse@nasdse.org. ■

NASDSE played a major role in the reauthorization of the Individuals with Disabilities Education Act (IDEA) in 1997.

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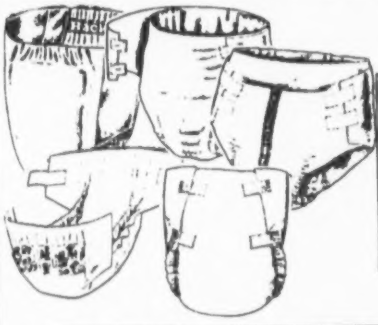

PART 2 OF EP'S INTERVIEW WITH JANE BROWNING

Putting Families First

Jane Browning, executive director of the President's Committee on Mental Retardation, has had a lifelong devotion to advocacy, both personally and publicly. In the second part of EP's interview with her, Jane talks about what she learned from her own parenting experience with her son Paul, who has Down syndrome, and the role the PCMR and other agencies should play in the future of all families.

Bringing up Paul

A big concern for Jane was getting the proper education for her son. Living in Arkansas, and later in Maryland, Jane made Paul's education a top priority. He began early intervention in Arkansas when he was an infant.

"From the moment he was born, I was hooked up to Parent to Parent. At six weeks he was in this early intervention program that was from 9 until 2 every day. He was included in regular child care from the start as well, and over time, the regular program replaced the special program. As the president of the Arc of Arkansas, I created a program called "Project KIDS" (Kids in Integrated Daycare Services). My husband got onto the board of directors at Frances Allen School, which Paul attended. The school put their professional services out into satellite programs all over the city. They were serving three times as many children as before. They would go to where the children were; they would do integrated speech therapy with little groups of children.

"Paul was very successfully included in kindergarten—a full day with inclusive speech therapy. We made them learn how to do that. The speech therapist was not keen on doing it at first, but he learned. The Project KIDS program became a model that went statewide and helped the planning process for infants and toddlers ."

Helping to blaze trails in Maryland

When Jane and her family moved to Maryland, her son had already had an IEP (Individual Education Plan) that called for full inclusion in the regular classroom. Jane remembers that in Maryland, without his IEP, Paul never would have been included in a regular classroom. Jane says that he became the first child with Down syndrome to be fully included in a regular classroom in Baltimore County because he brought along his IEP.

"When we arrived in Maryland, Paul was in fifth grade, so he had been in many different schools and school districts, with new people all the time. When we came to Anne Arundel County, there was a family whose son had Down syndrome and was a year ahead of Paul. They, too, were pushing very hard for inclusive education. Finally, Paul did not have to be the pioneer everywhere he went! He was following in the wake of this older boy, which is where he is today. This is great for me, too, because I've got a teammate, a partner-mom who does everything with me."

The President's Committee and a look at poverty

In 1994, President Clinton formulated the President's Committee on Mental Retardation for his administration. Because she had already been the governor's appointee to the Developmental Disability Council in Arkansas, Jane Browning was appointed as a member to the PCMR, where she served for two terms before being appointed executive director.

"In 1969, the PCMR published a book called 'The Six Hour Retarded Child.' It was the first publication linking poverty to mental retardation. It was a very sensitive subject then as it is now, but it is true that probably 80 percent of all mental retardation has its roots in socio-environmental concerns.

"It's a population that no one has claimed and everyone has forgotten. We know that these people are out there experiencing these social problems, and we have social programs to deal with their problems, but we don't connect the knowledge of the disability field with the human service agencies that are created to help these people survive. So the PCMR decided to start doing some bridging.

From left to right: "Captain" Paul Browning, Jane Browning, and friends Errin and Chris Perlmutter.

Advice for young parents

From her experience advocating almost every step of the way for her son Paul, Jane Browning has gained substantial practical wisdom which she would like every parent of a child who has a disability to know:

- "Start early. It is never too soon to begin seeking support in the community. Parents often get bogged down in the grief process and this can slow them down in getting help. Work through your grief and put the child's interests first."
- "Rely on your own instincts. What you feel is the best thing for your child probably is the best thing. You are the expert on your child."
- "Be skeptical of professional advice. Take a stand and put your opinions forward."
- "You know your child better than anyone else, and you have an equal place at the table."
- "You are capable—don't be intimidated."
- "Elevate your expectations. It's easy to be bullied into settling for less. It's amazing what positive expectations toward higher goals can achieve. I have seen it with my son. He has done amazing things when his teachers demanded it of him."

"The director of the TANF (Temporary Assistance to Needy Families) Program came to the Poverty Conference we held in February, and spoke to the audience and interacted with the members of the disability community who were there. PCMR followed up, and a group of disability-policy activists got together with the director of TANF to talk about how to serve and support these people who need extra help. It's great that we've got resources to help get people jobs. Now let us help figure out how to do it so that it will work. The disability community hasn't been looking at these families as belonging to their clientele either.

"On the other side, the anti-poverty groups have been very reluctant to label children in that community as having mental retardation. It's such a stigma-bearing identity. These children are not being given opportunities or proper schools—and these conditions are holding them back. You can call it whatever you want, but we in the community that work with people with mental retardation can help maximize the potential for a child in that community.

"It's a politically sensitive issue. We are trying to figure out how to bridge those communication gaps without being offensive to any group. That's where I see my work in the future. I think we need to get the disability groups to recognize that these populations are out there, and then claim them. My targets include law schools and foster care systems in state governments and healthcare providers, even the anonymous primary care providers that are springing up everywhere. They have a responsibility for identifying children, too."

Prevention

Jane has recognized the need for prevention and preventive programs such as Head Start. Head Start has expanded so

continued on page 88

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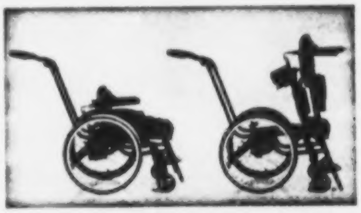

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The experts in standing

Circle #66

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that very young children are included. The fact that they have always included families is one of the critical reasons why the program is so essential. Jane believes that families should be involved at their children's schools and in their education. However, she notes, as soon as her children entered the middle and high schools, the environment became unwelcoming to parents. Jane's view is that schools need all the help they can get, and there are parents out there who are willing to give it.

"Let me state, for the record, that prevention has become a sort of 'dirty' word in the disabilities field because it offends people with disabilities to think that they wouldn't be wanted, that they are not accepted the way they are. I am not advocating the termination of life if there is anything indicating that they are less than perfect. But I do want to help ensure the healthiest possible start for every child. If you are a child with Down syndrome, then let's make you a healthy child with Down syndrome.

"Let's eliminate the environmental toxins that poison their little systems and make them impulsive or hyperactive or aggressive in school—that diminish their cognitive capacity. I am especially energized about fetal alcohol syndrome, because it is completely preventable, and it is such a disastrous disability."

Helping parents

As a parent advocate, Jane learned first hand that parents need all the help and support they can get, and to know that they have somewhere to turn when they think they have nowhere left to turn. She notes that the PCMR is always alert to parents' needs when their rights or the rights of their child with a disability are threatened.

"The PCMR does a lot of constituent work. If parents are not getting what they need, if they are not getting satisfaction at the local level, we are a recourse. We try to help. I have referred cases to the Justice Department and the Department of Education. The PCMR welcomes parents to exchange information with us—we want to know what's happening in these situations." ■

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Circle #95

LEGISLATIVE UPDATE

by David Chamalian

CONSTITUTIONALITY OF ADA IN QUESTION

Over forty cases in the past ten years have called into question Congress's power to impose the regulations of the Americans with Disabilities Act of 1990 (ADA) on states. A recent addition to that number is *Garrett v. University of Alabama*, a disability-discrimination case. Garrett is a consolidation of two employment-discrimination cases filed against the state of Alabama—one by a woman with breast cancer and another by a man with severe asthma—which will test the very constitutionality of the ADA by challenging the Supreme Court to decide whether Congress had the constitutional authority under the Fourteenth Amendment to enact the ADA against the state of Alabama. If the Court finds that Congress did not have such authority and issues a ruling in favor of the state of Alabama, disability-rights advocates, including National Protection and Advocacy Systems (NAPAS), claim that the ADA's mandates of community-living integration, public-facilities access, and employment would be weakened. Arguments for this case are scheduled to be heard in October.

For more information about the case, log onto the US Department of Justice Web site, http://www.usdoj.gov; click on "search;" go to the bottom section of the page, where it says "search within all government agencies" and click on "connect to search page;" in the search box type "Garrett v. University of Alabama" and click in the box called "Exact word phrase entered;" click either item 1 or 2; and then click on "ADA Litigation."

For more information on the Americans with Disabilities Act, log onto the following URL address: http://www.usdoj.gov/crt/ada/adahom1.htm.

CLINTON-GORE ADMINISTRATION ANNOUNCES NEW INITIATIVES FOR HOME- AND COMMUNITY-BASED SERVICES AND HOUSING OPTIONS FOR PEOPLE WITH DISABILITIES

Below is a summary of some of these initiatives:

- Housing—$50 million will be spent to aid states in developing plans to provide people with disabilities the services they need in the most integrated setting appropriate to their needs. "No one should have to live in an institution or nursing home if they prefer to live in the community with the right support," said Gore.
- The Olmstead Supreme Court decision—Guidance will be proferred to states to ensure more rapid initiation of and access to essential home- and community-based services as governed by this decision.
- Community living—Nearly $20 million will go toward increasing the availability of accessible, affordable housing for people with disabilities and providing necessary support to individuals transitioning from institutional to community living.
- Employment—Incentives to work will be expanded by extending earned-income limitations.
- Home ownership—The US Department of Housing and Urban Development (HUD) will encourage its lender partners to show "increased, but prudent flexibility" when underwriting the loan applications of people with disabilities.

For more information on these and other initiatives, log onto http://www.whitehouse.gov.

IMPROVED STATE SERVICES AWARDED TO CHILDREN WITH DISABILITIES

The US Department of Education recently announced that it has awarded nine state grants, totaling $7.5 million annually for five years, to help improve special and general educational services for children with disabilities. Earmarked to receive these grants are Alaska, Connecticut, Illinois, Montana, Minnesota, Nebraska, North Carolina, North Dakota, and Oklahoma. Last year $18 million was granted to 18 other states for similar purposes.

In a statement released to the press, Judith E. Heumann, assistant secretary for Special Education and Rehabilitative Services, had the following to say about the aim of the grants: "This valuable program helps states and schools address such critical issues as teacher shortages and the need for highly qualified personnel. As we continue to work toward a common goal of educational excellence for all children, we see the difference that this form of assistance can make in our schools and in the lives of students with disabilities."

The grants were made under the State Improvement Grant Program, which requires states to use 75 percent of the money for the professional development of educators, administrators, and related services personnel. Remaining dollars can be used for technical assistance and disseminating information about the best educational practices to improve results for children with disabilities.

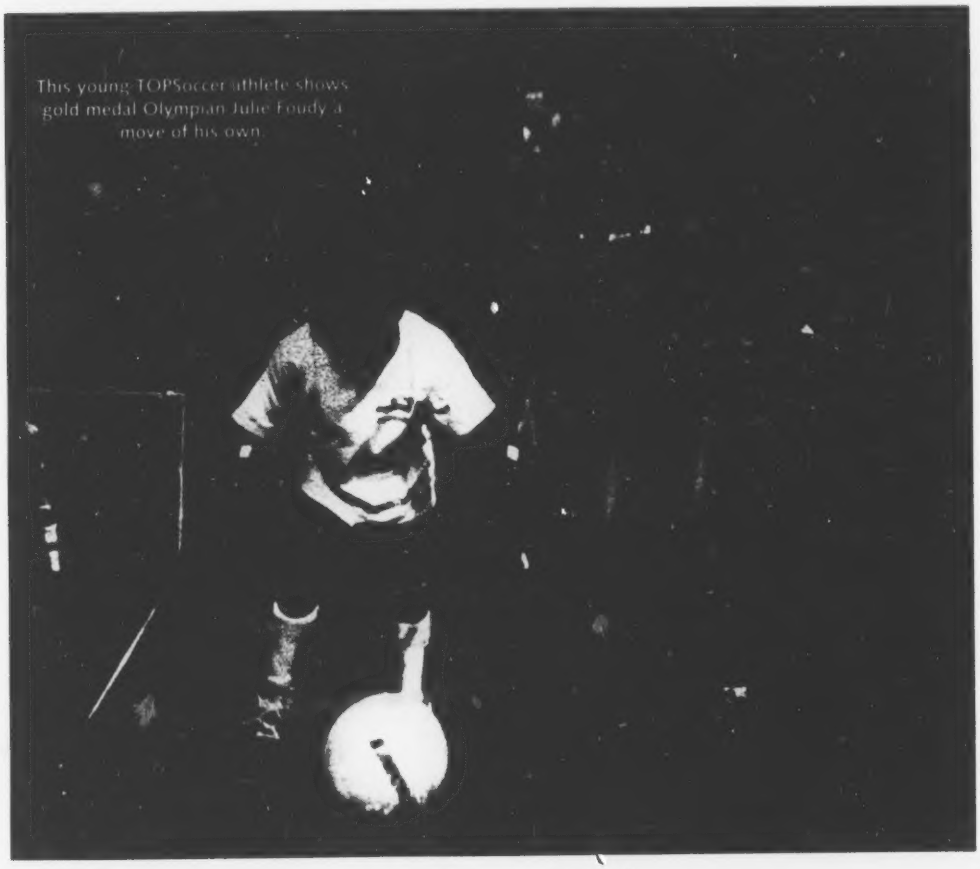
"Top" of Their Game

With the help of a top Olympic athlete, US Youth Soccer continues to open the field of play of this highly popular sport to youngsters with disabilities.

by David Chamalian

Participation in soccer among kids of all ages has been staggering in the past decade. According to US Youth Soccer, a national nonprofit and educational organization whose mission is to promote the emotional, mental, and physical development of America's youth through the game, soccer remains the fastest growing team sport among kids and teens in the nation.

Back in 1992, after recognizing the potential growth of soccer in the country and envisioning the benefits that playing soccer could bring to youngsters with disabilities, a parallel program to US Youth Soccer called TOPSoccer (see EP July 1999) was launched. Since that time, TOPSoccer, which stands for The Outreach Program for Soccer, a community-based outreach and team-placement program for children with special needs between the ages of 4 and 19, has brought 8,000 young participants with disabilities off the sidelines and onto the field.



This young TOPSoccer athlete shows gold medal Olympian Julie Foudy a move of his own.

On the field

TOPSoccer athletes experience the physical activity and emotional thrills inherent in any fun game of soccer, but they are also afforded the accommodations necessary to meet their special needs. First, teams are formed based on needs and abilities, not age, which takes into consideration the varied pace at which children with different disabilities develop. Second, the emphasis of the program is on building self-esteem and motor skills, having fun, and fostering camaraderie, rather than winning or losing.

To complement the participation of youth with disabilities, TOPSoccer also offers a "buddy" volunteer component, which pairs up each player with a nondisabled youth soccer athlete for extra assistance in learning and playing the game. The positive benefits of this one-on-one partnership are mutual, not only helping the TOPSoccer players develop their bodies and improve their skills, but, according to the parents of the "buddy" volunteers, instilling in their children a sense of pride in their volunteerism.

Passing on the word

To help bring soccer closer to the approximately 4.5 million children in the US with disabilities, TOPSoccer and their first national sponsor, Uniroyal® Tire, have recently enlisted the help of Co-captain and Olympic gold medalist on the US Women's National Team Julie Foudy. Ms. Foudy, who is a twelve-year veteran of the national team and now the official spokesperson of TOPSoccer, kicked off a new public-awareness campaign for the program in May by holding a mini-clinic in New York City, where she offered her expertise and shared her experiences with the East Hudson TOPSoccer League. The national sponsorship and fundraising efforts are aimed at providing much-needed funds for equipment and uniforms.

> **First, teams are formed based on needs and abilities, not age, which takes into consideration the varied pace at which children with different disabilities develop.**

Speaking on the momentum that the TOPSoccer program is enjoying nationwide, Ms. Foudy is excited about the rewards her work getting children with mental and physical disabilities interested in playing the game will bring her. "These kids are doing things most never dreamed possible. And when it comes to scoring a goal, their excitement will rival a World Cup goal any day."

continued on page 92

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continued from page 91

Organizing a local program: a goal within reach

For anyone interested in launching a TOPSoccer program in their area, US Youth Soccer recommends potential organizers first to establish the needs within the community and make contacts. Below are some of these recommendations:

- Identify the number of children with special needs in your area and determine how your program can help fulfill those needs
- Ensure that the facilities you plan to use can accommodate children with special needs
- Consult a soccer insurance carrier
- Contact established programs and institutions for assistance: US Youth Soccer, Special Olympics, United Cerebral Palsy, Shriners, local schools and universities, etc.
- Compile a list of volunteers
- Plan for promotion and advertising
- Contact other US Youth Soccer and TOPSoccer representatives and use them as resources

Once your preparations are complete, starting the program is the next step:

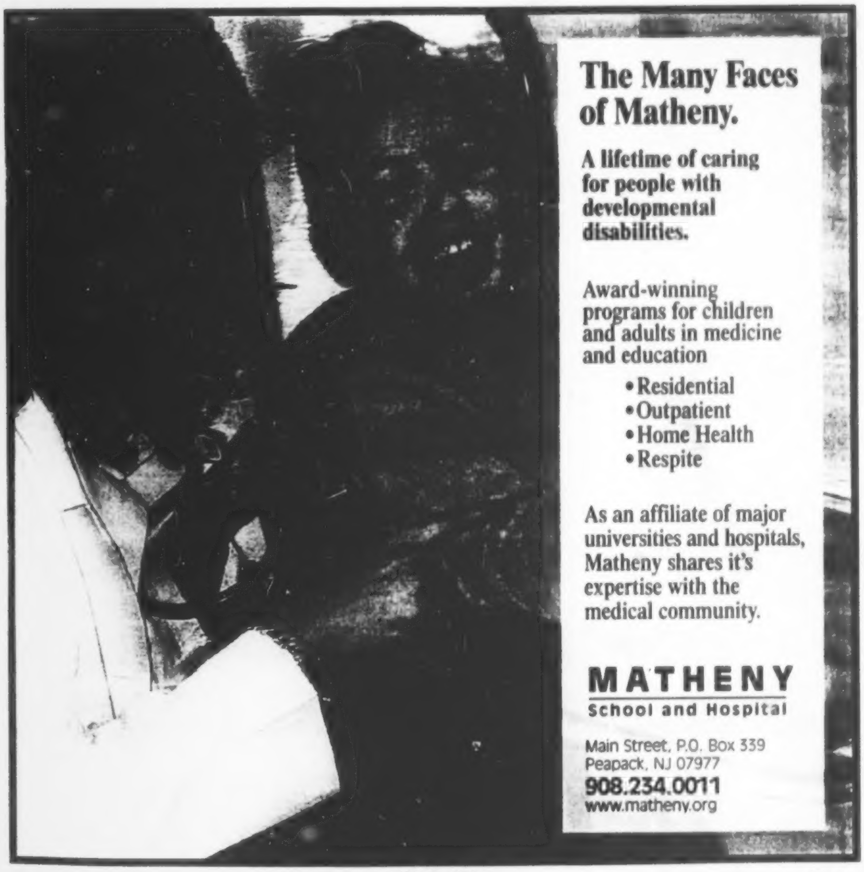
- Recruit coaches—use your resources for assistance
- Group the players into teams—by ability, not age
- Determine the length of the program (usually 6-8 weeks)
- Establish the rules
- Be prepared for a modest beginning
- Adjust the field for smaller teams
- Consider both indoor and outdoor facilities or a soccer camp program.
- Prepare a parallel skills program for those who cannot play in games
- Keep your costs low and affordable, and most important,
- Make it fun! ■

For a list of your state's Youth Soccer Association, log onto http://www.youthsoccer.org/network/states.cfm.

Julie Foudy instructs a youngster on the skill of dribbling a soccer ball at a recent TOPSoccer clinic she held in New York City.

For more information on TOPSoccer and starting a program in your community, contact:

Jim Cosgrove
Director, Soccer Operations
US Youth Soccer
899 Presidential Dr., Ste. 117
Richardson, TX 75081
Phone: (800) 4-SOCCER
(476-2237)
Web site:
http://www.youthsoccer.org
(click on "On the Field")



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MEDICAL RESEARCH UPDATE

BY DAVID CHAMALIAN

NEW THERAPY FOR PEOPLE DISABLED BY STROKE

A recent study reveals the promise of a new rehabilitative therapy for people who have limb paralysis due to stroke. After a stroke, some cells that may control limb movements remain in shock and, therefore, cannot function. According to the study's authors, each time a person tries to use the limb with paralysis and fails, the failure gets reinforced and the limb falls into a state of "learned helplessness."

The new therapy, called constraint-induced-movement therapy, forces the person to use the affected limb to do familiar, everyday tasks. Edward Taub, MD, a neurologist at the University of Alabama-Birmingham, and his staff have found that by immobilizing the unaffected arm for a strict regimen of six hours a day and at least two weeks straight, the brain can relearn to use the affected arm. Results of the 13-person study showed that all of the participants had regained nearly full use of their affected limbs after the therapy (preliminary tests show that the therapy is as effective on legs as it is on arms, but more studies are being done to confirm this.). The study also found that the therapy worked for individuals who have lived decades with limited use of a limb due to stroke.

Stroke expert and Duke University Medical Center Professor Larry Goldstein, MD, however, cautions that the study has "big limitations" because there was no control group, and is based on a significantly small number of people. "Is it promising?" he asked. "Yes. Is it proven? No." This study was published in the June 2000 issue of *Stroke*.

SHUNTING IN YOUNG ADULTS WITH SPINA BIFIDA PROVES POSITIVE

Researchers who studied 23 young adults with spina bifida and hydrocephalus (which is assumed to be controlled) have discovered that cerebrospinal fluid shunting can improve neuropsychological functioning. The results of studies done six months before and six months after the surgical placement of a shunt show "significant improvements ..... in verbal and visual memory, motor coordination, and attention and cognitive flexibility." Younger children with hydrocephalus may benefit most from shunting, say researchers, due to the "greater plasticity of the young brain." According to Maria Antonia Poca, MD, and her colleagues at the University of Barcelona, the "improved cognitive functions will probably lead to clinical, educational, and social benefits." To view this study, refer to the May 2000 issue of the *Journal of Neurology, Neurosurgery, and Psychiatry*.

YOUNG ADULTS ON DIALYSIS ADVISED TO MONITOR CORONARY-ARTERY CALCIFICATION

According to results of electron-beam computed tomography (CT)* tests performed on 39 people (ages 7 to 30) with end-stage renal disease, researchers have discovered, among the study participants between ages 20 and 30, a proportionately high incidence (14 out of 16) of vascular calcification compared to results of tests done on a control group of 60 healthy young people (of which only 3 participants showed signs of the calcification.) Among the younger participants in the study (those under 20-years-old), however, there was no evidence of coronary-artery calcification.

William G. Goodman, MD, and his colleagues at the University of California-Los Angeles view the high levels of calcification found in the elder portion of the group as a function of the build-up of large doses of calcium that young people on dialysis take—up to 6,000mg/day—to rid the bloodstream of phosphorus, which is a common complication of renal failure. Though still unproven, Dr. Goodman suggests a decreased dependence on calcium to purge the blood of phosphorus. "We would encourage a reduction in the amount of calcium that is used, and perhaps patients should rely on other compounds that bind phosphorus that do not contain calcium." This study can be found in the May 18 issue of the *New England Journal of Medicine*. *(A CT scan is a method of taking pictures of the inside of the body using an ultra-thin x-ray or electron beam.

RESEARCH FOR PARENTS OF CHILDREN WITH DISABILITIES PROVES THE IMPORTANCE OF EMPATHY AND SUPPORT

Based on analysis of audio-taped interviews, two researchers reaffirm the positive impact mutual support can have among parents of children with disabilities. After studying the parents of 63 children born with a congenital upper-limb deficiency, S.M. Kerr and J.B. McIntosh, both from the University of Glasgow in Scotland, found that during the first few months after their baby's birth, support from family, friends, and health professionals alone was not sufficiently helpful to the parents. To cope with the feelings of isolation and concern about the future, the research showed that parents of children with disabilities were only adequately supported upon making contact with other parents of children with disabilities—in this case, those whose children also had limb deficiencies. Such contact proved to be a much-needed stress-buffering influence, as it provided emotional, social, and practical support. The study, which can be found in the July 2000 issue of *Child: Care, Health and Development* in an article entitled "Coping When a Child Has a Disability: Exploring the Impact of Parent-to-Parent Support," concluded that parents of children with disabilities are "uniquely qualified to help each other." The article also encourages healthcare professionals to recognize this fact and take steps to connect parents with the appropriate organizations and contacts that can offer support.

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The WCD
Takes a Universal Approach

by Gale Jurasek

EP's First Annual World Congress & Exposition on Disabilities (November 10-12, 2000) in Atlanta, Georgia, is an event that will bring together individuals with disabilities, their families, and professionals to take part in a broad range of presentations. The WCD reflects the philosophy that the exchange of information and ideas among parents and professionals is of paramount importance to the wellness of individuals with special needs and those who care for them. These two groups have a tremendous amount to share with and learn from one another, and many in the special needs community will attend to benefit from this interchange. The presentations are varied in scope and focus. They are separated into four tracks: Medical, Education, Family and Direct Support Professional, and Adapted Physical Activity. Below is a small sampling of the presentations at the WCD.

WORLD CONGRESS & EXPOSITION ON DISABILITIES

WCD

The Medical Track

- **Mitochondrial Disorders** *Speakers: Darryl DeVivo, MD, Babies Hospital, Columbia Presbyterian Medical Center, New York, NY; John Shoffner, MD, Children's Healthcare of Atlanta at Scottish Rite, Atlanta, GA*—A discussion of the various ways in which mitochondrial disorders present themselves. Also covers diagnosis, recurrence of risks, prenatal diagnosis, and therapeutic options.
- **Feeding Difficulties in Children With Down Syndrome** *Speaker: Beverly Witt, PT, Orange Grove Center, Chattanooga, TN*—Identifying and managing feeding difficulties in children with Down syndrome and other developmental disabilities. Topics include how motor skills affect eating, providing adequate nutrition, and when and how to use supplemental or replacement nutrients.

The Education Track

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Speakers: Kelly Maxwell, PhD, and Syndee Kraus, BA, Frank Porter Graham Child Development Center, University of North Carolina, Chapel Hill, NC—An overview of family-centered practice, covering description, development, and implementation of policies and procedures that create family-centered practices in an elementary school setting. Will also cover measuring and assessment tools, and family feedback.

- **Discipline and Behavioral Interventions** *Speakers: Doug Lee, MD, Emory University, Atlanta, GA; Cathleen Piazza, PhD, Kennedy Krieger Institute, Baltimore, MD/The Marcus Institute, Atlanta, GA; Cathi Trapani, PhD; Alan Weintraub, MD, The Marcus Institute, Atlanta, GA*—A discussion of the methods of managing behavioral problems in the classroom setting. Topics will include differentiating among behavioral disorders; intervention strategies that work, assessment and management of behavior problems, and working together with parents and physicians.

Family and Direct Support Professional Track

- **Reimbursement** *Speakers: Merv Watkins, President and CEO, Convaid, Palos Verdes, CA; Dan Fedor and Martin Szmal, Reimbursement Specialists, Pride Mobility, Exeter, PA*—A guide to obtaining reimbursement for mobility devices and other equipment. Discussions include: "When a stroller is not a stroller," a look at Medicaid and Medicare regulations, the prescriber's role, applying for reimbursement, and the procedure for appeals.
- **Evidence-Based Healthcare** *Speakers: Charlene Butler, EdD, Consultant on Educational Assessment Issues, Seattle, WA; Belinda Abbruzzese, Alicia Davis Cooper, Jane Fox, Charlene Liggins, and Fatema Salam, project team, "Assessing the Needs of Metro-Atlanta Children with Cerebral Palsy and Their Families," School of Public Health, Emory University, Atlanta, GA*—Because managed care organizations, other insurers, and physicians are using evidence-based healthcare (outcomes management) to choose treatments, this discussion will explain the concept to parents and caregivers so they can apply the same methodology.

Adapted Physical Activity Track

- **Creating Movement Programs for Young Children of All Abilities** *Speakers: Diane Craft, State University of New York, Cortland, NY; Renee McCall, Main Street Early Education Program, North Syracuse, NY*—How to lead meaningful, inclusive, developmentally appropriate games and activities for preschoolers with disabilities.
- **Above and Beyond—The Steps to Building a Playground for All Children** *Speaker: Jean Schappet, Boundless Playgrounds, Bloomfield, CT*—How a small group of interested people can develop and build an inclusive playground. ■

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Special Report — PART TWO

NEWBORN SCREENING

Tandem Mass Spectrometry

by Charles R. Roe, MD, and Lawrence Sweetman, PhD

Until very recently, routine screening of newborns for inherited metabolic disorders was limited to three to five disorders. Now, with the new method using tandem mass spectrometry (MS/MS), more than 30 of these diseases or disorders can be easily detected from a drop of blood. Parents of children with these disorders rarely have any family history to suggest the possibility of having an affected child. This is because these conditions are "autosomal recessive," which means that each parent carries a gene for the disease but is not affected. Each new baby born to those parents has a 1 in 4 chance of inheriting the defective gene from each parent. Unless the family has already had a child affected with one of these disorders, there is no warning.

Inborn errors of metabolism can affect a child in a variety of ways: they can appear as illnesses with recurrent episodes of low blood sugar, which can produce coma or sudden death following simple infections; as severe muscle pain and cramping requiring repeated hospitalizations, and possible severe kidney damage; as weak muscles and developmental delay often associated with epilepsy; as heart enlargement to the point of heart failure and death at 2 to 5 months of age; as nerve and muscle involvement interfering with walking and vision; as seizures, hair loss, and developmental delay; or even combinations of several of these problems. Even though the same gene is affected, some of the disorders can manifest themselves in two or three different ways, or "phenotypes." Different phenotypes of the same disease usually do not occur in a single family, but different families can have the same defect while their children have different problems. A good example of this is Very Long Chain Acyl-CoA Dehydrogenase deficiency (VLCAD). The children in some families may have only problems with blood sugar; children in other families may have mostly the muscle problems often associated with problems with blood sugar; while other families may lose children to sudden onset of severe heart disease before 6 months of age.

The time that symptoms appear is also very variable. The more severe forms of these conditions present in the first week of life and are often lethal. Other forms may not appear until the child has an ear infection or some other stress to his system, or until a child is unable to eat for more than twelve hours. Some forms can first appear as an adult. Often, when one child is finally diagnosed with a disorder, testing siblings will reveal that there is another affected child in the family who has not yet had an episode of illness. Testing siblings of affected children is, therefore, urgent. It is also not unusual for a mother to be pregnant at the time one of her children is found to have one of these diseases. It is important to be aware that prenatal diagnosis is also available for most of the disorders detected by MS/MS screening. This permits detection of conditions in the unborn child (or, happily, the elimination of concern for that pregnancy). When a baby is found before birth to be affected, treatment can be initiated at birth to prevent many of the problems which would otherwise occur—including sudden, unexpected death.

Supplemental newborn screening using MS/MS is a single test that can detect more than 30 inherited metabolic disorders by measuring two groups of compounds in dried blood spots. One of these is amino acids, the building blocks of protein; elevated levels of specific amino acids can indicate the presence of inherited amino acid disorders and urea cycle disorders. The other group is acylcarnitines. These chemicals come from fatty acids and other organic acids and also from amino acids. High concentrations of individual acylcarnitines can indicate more than 20 inherited disorders.

The combined incidence of the 30-plus metabolic disorders is estimated to be about 1 in 5,600 babies, not including phenylketonuria (PKU). Most of the time, therefore, the screening result is normal. In about 1 out of 100 screens, if a slight elevation of amino acids or acylcarnitines is detected, a repeat blood spot usually indicates that the initial elevation was only temporary. If the elevation is still present when repeated or the initial screening result was clearly abnormal, then a metabolic disorder is very likely. For a few of the disorders, such as Medium-Chain Acyl-CoA Dehydrogenase deficiency (MCAD), the screening pattern is very specific and diagnosis is simplified; while for others, the elevations may be caused by more than one metabolic disorder. Therefore, additional confirmatory testing must be done to diag-

Sponsored in part by an unrestricted grant from Sigma Tau Pharmaceuticals, Inc.

nose the exact metabolic disorder and to allow proper clinical treatment.

The per-child cost of screening newborns by MS/MS is low because the procedure can be highly automated, and analysis of results is largely computerized because normal newborns have fairly narrow ranges for the compounds. The optimum time for collecting the dried blood spots is believed to be 2 to 3 days of age, since many of the disorders will show maximum abnormality at this time. Early detection of an abnormality by the screening before the baby has clinical symptoms should lead to earlier clinical management and a better clinical outcome.

Which parents should consider screening their newborn baby? If a family has a history of a particular metabolic disorder, MS/MS screening is appropriate, depending upon the particular disorder. This decision should involve the pediatrician or geneticist, who may also suggest more specific diagnostic testing. Families with a history of SIDS (or unexplained childhood death) should consider the screening, since as many as 3 out of 100 cases of SIDS or unexplained death may have been due to a metabolic disorder. But parents with no family history of a metabolic disorder should also consider the screen: most affected babies are born to parents who do not know they are carriers. Having already had healthy children does not rule out the possibility that the next child may be affected. The older children may be normal, carriers, or even affected with a metabolic disease that has not yet manifested itself.

When should parents consider having supplemental MS/MS newborn screening of their baby? This should be considered during pregnancy, well before delivery. This screening is relatively new and not yet widely available, so it is best to make arrangements ahead of time. Some states, including Massachusetts, North Carolina, Pennsylvania, and Wisconsin, now perform part or all of the MS/MS screening for most newborns. Additional states are preparing to offer this screen and parents should first find out if it is offered in their state. If not, the screening can be performed by other laboratories *(see box)*.

What if the baby or child is older, and not ill or exhibiting symptoms of a disorder, but the parent has just heard about this screening? Testing can be done at any age. Although many of the disorders will cause clinical symptoms at an early age, some may not show symptoms for months or years. Therefore, it is important to screen all siblings, or to perform more specific diagnostic tests of siblings of any babies found to have one of these disorders. State newborn screening programs may not do MS/MS screening for older infants and children. If desired, materials can be provided to the parent or pediatrician so that the test can be obtained for an older infant, child, or young adult *(see the same box)*.

What if a child has clinical symptoms? The MS/MS screen may or may not be appropriate, depending on what the symptoms are and what diagnostic tests have been done already. For example, if a plasma amino analysis, a plasma or dried blood spot acylcarnitine profile, and a urine organic acid analysis have been done, the MS/MS screen may not offer additional information. Parents should discuss with their pediatrician, genetics counselor, or other specialist whether the MS/MS screen for the 30-plus disorders could be helpful. An acylcarnitine profile done by MS/MS for a child with clinical symptoms is a more sophisticated test and is more thoroughly reviewed by a specialist than the simpler MS/MS newborn screen. As supplemental newborn screening by MS/MS becomes widespread in the coming years, the need to screen older children will decrease.

Additional information on MS/MS screening is available from:

Institute of Metabolic Disease
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Dallas, TX
Phone: 1-800-4-BAYLOR
Web site:
http://www.baylorhealth.com/newbornscreening

Neo Gen Screening, Inc.
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Charles R. Roe, MD, is Medical Director of the Institute of Metabolic Disease at Baylor University Health Center, Dallas, TX. Lawrence Sweetman, PhD, is Director of the Mass Spectrometry Unit, Institute of Metabolic Disease at Baylor University Health Center, Dallas, TX.

Metabolic Disorders Found Through Newborn Screening

As Drs. Sweetman and Roe discuss in their article, a newborn screen can be performed after the neonatal period, although the accuracy will be somewhat reduced as the child gets older. Other tests can be performed to pinpoint specific disorders; however, testing decisions should involve the child's pediatrician as well as any specialists who might have been consulted.

Tandem mass spectrometry (MS/MS) can discern approximately thirty inborn errors of metabolism. Many of these conditions, especially the organic acidurias, are extremely rare; some have fewer than 100 known cases worldwide. A brief description of each follows, with treatment information where available. —The Editors

AMINO ACID DISORDERS

Argininosuccinic Aciduria—The disorder is extremely rare, affecting fewer than 100 people in the US. Symptoms are hyperammonemia accompanied by lack of appetite, vomiting, listlessness, seizures, and coma. Onset is usually at birth, but symptoms may not be noticeable for days or weeks. Left untreated, brain damage, coma, and death will occur. Treatment includes a high-caloric, protein-restrictive diet, arginine supplementation, administration of sodium benzoate and sodium phenylacetate. Dialysis may be necessary.

Citrullinemia—Citrullinemia stems from a deficiency of argininosuccinic acid

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synthetase. Epidemiology, symptoms, and treatments are the same as those for argininosuccinic aciduria.

Homocystinuria—The most common cause of homocystinuria is a deficiency in the enzyme cystathionine-synthase. Incidence is 1 in 200,000, but prevalence is 1 in 82,000 in Great Britain, Ireland, and Australia. Among the symptoms are thromboembolism, optic lens dislocation (which may occur even with treatment), scoliosis, osteoporosis, mental retardation, seizures, and psychiatric disturbances. Approximately 50 percent of untreated individuals die before age 25. Treatment may include a methionine-restricted, cystine-supplemented diet, as well as large doses of Vitamin B6.

Maple syrup urine disease (MSUD)—MSUD is caused by abnormal metabolism of three branched-chain amino acids. Although the overall incidence of the disorder is 1 in 200,000, it is about 1 in 760 among Mennonites. Symptoms include an odor of maple syrup in the urine, poor feeding, lethargy, coma, and mental retardation. Death commonly occurs within three months of birth. Treatment requires dietary restriction of branched-chain amino acids, necessitating a complicated formula and intensive monitoring.

Phenylketonuria (PKU)—This metabolic condition results from the lack of an enzyme in the liver that converts phenylalanine to tyrosine. Incidence is 1 in 12,000 and is most prevalent among people of Irish or Scottish descent. Symptoms include severe mental retardation, seizures, autistic-like disorders, and a peculiar odor; lifespan is reduced. Treatment consists of lifelong dietary management and counseling.

FATTY ACID DISORDERS

These are rare autosomal recessive conditions in which the body cannot oxidize fatty acids because an enzyme is either missing or not functioning correctly. Many of the effects are attributed to secondary carnitine depletion.

Carnitine Palmityltransferase Deficiency Type II (CPT II)*—CPT II affects males more than females and is more apparent in people with diabetes or malnutrition. Fasting may trigger symptoms. It usually becomes apparent in adults, but a more serious form affects children. Major symptoms are myalgia, fatigue, and reddish-brown urine. Treatment includes a diet low in proteins and fats and high in carbohydrates, adequate hydration, avoidance of fasting, and keeping warm. Carnitine supplementation may be effective.

Glutaric Acidemia Type II--Multiple Acyl-CoA Dehydrogenase Deficiency—This disorder manifests in three forms; the neonatal is most serious and often fatal within a few weeks. Symptoms of neonatal GA II in infants with congenital anomalies may include severe hypoglycemia, metabolic acidosis, hypotonia, hepatomegaly, and, often, an odor of "sweaty feet." It can be fatal within the first week. When congenital anomalies are absent, symptoms may be milder and untreated infants may survive for a longer period. Treatment includes a high-carbohydrate, low-protein, low-fat diet, and eating frequently; supplementation with riboflavin and carnitine may be helpful.

Long Chain Acyl-CoA Dehydrogenase Deficiency (LCAD)—LCAD in infants is typified by failure to thrive, enlarged liver, enlarged heart, metabolic encephalopathy, and hypotonia. Unless treated immediately it is generally fatal. Treatment is a high-carbohydrate, low-fat diet; administration of medium-chain triglyceride oil (MCT oil), supplementation with carnitine and/or riboflavin, and avoidance of fasting.

LCHAD–3-Hydroxy Long Chain Acyl-CoA Dehydrogenase Deficiency—Typical symptoms of LCHAD are hypoglycemia, lethargy, failure to thrive, and developmental delay, often accompanied by hypotonia and cardiomyopathy. Some SIDS events are likely caused by LCHAD. Early identification and treatment can prevent life-threatening episodes. Fasting should be avoided and a high-carbohydrate diet followed.

Medium Chain Acyl-CoA Dehydrogenase Deficiency (MCAD)—MCAD is characterized by recurrent episodes of metabolic acidosis, and by hypoglycemia, lethargy, and coma. Symptoms typically begin in infancy or early childhood. MCAD occurs mostly among Caucasians of northern European background. Initial episodes are often triggered by fasting and may lead to death in 20 to 25 percent of those affected. About one in 100 SIDS deaths are probably a result of MCAD. Avoidance of fasting is imperative; use of glucose IV is required when food cannot be tolerated. High intake of medium- and long-chain fatty acids should be avoided. Supplemental carnitine is recommended for children.

Short Chain Acyl-CoA Dehydrogenase Deficiency (SCAD)—Presenting symptoms of SCAD are failure to thrive and hypoglycemia; over time, development is delayed. As with the other fatty acid disorders, fasting can be a precipitating event and must be avoided. Diet must be monitored and supplemental carnitine should be administered.

Very long Chain Acyl-CoA Dehydrogenase Deficiency (VLCAD)—VLCAD's initial manifestations may include hypoketotic hypoglycemia, hepatocellular disease, and cardiomyopathy; fatal infantile encephalopathy may be the only indication of the condition. Attention to diet, avoidance of fasting, and supplemental carnitine comprise the treatment.

ORGANIC ACID DISORDERS

This is a group of autosomal recessive conditions with exceedingly limited incidences.

2,4-Dienoyl-CoA Reductase Deficiency*—This is a deficiency in an auxiliary enzyme of beta-oxidation. Primary symptoms are neonatal hypotonia and respiratory acidosis. Treatment calls for dietary restrictions and carnitine supplementation.

3-Hydroxy-3-Methylglutaryl-CoA Lyase Deficiency*—If this disorder is untreated, it is likely to result in death during childhood. Symptoms may include metabolic acidosis, hypoglycemia, sensitivity to dietary leucine, carnitine deficiency, hepatomegaly, fever, somnolence, and coma. Treatment involves restriction of leucine, supplementary glucose to prevent hypoglycemia, and carnitine supplementation.

3-Ketothiolase Deficiency*—The main symptom of this disorder is recurrent, severe metabolic acidosis. Sodium bicarbonate and intravenous fluids are the usual treatment for acidosis; dialysis may be needed. Carnitine supplementation has been helpful in some cases.

3-Methylcrotonyl-CoA Carboxylase Deficiency—Symptoms may include hypotonia, muscle atrophy, seizures, and dermatological changes. Dietary restrictions are the primary treatment; supplementation with carnitine and/or biotin may be valuable.

3-Methylglutaconyl-CoA Hydratase Deficiency*—Fewer than 50 cases of this disorder have been identified. It is characterized by delayed motor development, short attention span, and delayed development of speech. Other symptoms may include dementia and optic atrophy. There is a dearth of information concerning this disorder, particularly concerning treatment options.

Glutaric Acidemia Type I—This enzyme deficiency disorder is characterized by hypoglycemia, dystonia, and dyskinesia. After a period of apparently normal development, the disorder may appear suddenly and present as vomiting, metabolic acidosis, hypotonia, and central nervous system degeneration. Fewer than 100 cases are known in the US. Intravenous fluids and bicarbonate are used to treat acidosis; dialysis may be necessary. Dietary restrictions have had inconsistent outcomes. Carnitine supplementation may be needed.

Isovaleric Acidemia—With onset between birth and 1 year, IVA occurs in both acute and chronic forms. Symptoms of acute IVA are attacks of vomiting, lack of appetite, and listlessness; lethargy, neuromuscular irritability, and hypothermia are other characteristics. Episodes can be triggered by upper respiratory infections or by excessive consumption of high-protein foods. Treatment involves a protein-restrictive diet and carnitine supplementation. Oral administration of glycine is lifesaving and may permit normal growth and development.

Methylmalonic Acidemias [Adenosylcobalamin Synthesis Defects (CblA and CblB) and Methylmalonyl-CoA Mutase Deficiencies (mut- and mut+)]—An enzymatic defect in the oxidation of amino acids is the cause of these conditions, with an incidence of 1 in 50,000 to 1 in 100,000 live births. Symptoms usually begin in the first few months of life, and include lethargy, failure to thrive, vomiting, dehydration, respiratory distress, hypotonia, and hepatomegaly. Acute episodes may include drowsiness, coma, and seizures, with subsequent developmental delays. Treatment includes a carefully controlled diet including a low-protein regimen and/or restriction of isoleucine, valine, and threonine. Medical food supplementation may be needed, as may carnitine.

Multiple CoA Carboxylase Deficiency*—A deficiency of biotin, part of the Vitamin B complex, leading to multiple carboxylase deficiency. Incidence is 1 in 87,000. Symptoms include seizures, hypotonia, immune system impairment, skin rashes, hair loss, hearing loss and mental retardation. Treatment is oral biotin supplementation, which should be begun immediately upon diagnosis.

Propionic Acidemia—This disorder usually results in catastrophic illness beginning in the newborn period. Incidence is 1 in 100,000 live births. Primary symptoms include protein intolerance, vomiting, failure to thrive, lethargy, and profound metabolic acidosis. Brain damage, including coma and generalized seizures, and death result if not treated. Treatment includes protein restriction and often calls for supplementation by medical foods. Fluids and electrolyte therapy may be needed. Acidosis is resolved by sodium bicarbonate, or by dialysis. Secondary carnitine deficiency is likely to occur, requiring supplementation.

CYSTIC FIBROSIS

Cystic fibrosis is an inherited disorder that affects the mucus-producing glands. Mucus is thick, and can obstruct air passages in the lungs. It also causes dysfunction of the sweat and salivary glands, and blocks the enzymes secreted by the pancreatic duct, resulting in incomplete digestion. Incidence is 1 in 2,500 white live births and 1 in 17,000 African American live births. Cystic fibrosis can cause lung disease, failure to grow, clubbed fingers and toes, muscular weakness, and visual impairment. Treatment includes high doses of ibuprofen, antibiotics for pulmonary disease, and clearing of the airways with intermittent aerosol therapy.

ENDOCRINE DISORDERS

Congenital adrenal hyperplasia (CAH)—The most common form (more than 90 percent of all recognized cases) results from 21-hydroxylase deficiency. Incidence is 1 in 12,000, but may be as high as 1 in 5,000 among those of Italian background. CAH causes increased androgen production, resulting in ambiguous genitalia and virilization in girls and early virilization in boys. Other symptoms are accelerated skeletal maturation and ultimate short stature. Treatment is glucocorticosteroids.

Congenital hypothyroidism—This disorder is caused by inadequate production of thyroxine, a thyroid hormone. Incidence is approximately 1 in 4,000. Symptoms include mental retardation, growth failure, deafness, neurologic abnormalities, and hypometabolic activities. Treatment is levothyroxine, thyroid hormone replacement therapy, given orally.

OTHER DISORDERS

Biotinidase deficiency—See Multiple CoA Carboxylase Deficiency, above.

Galactosemia—This is an inherited disorder of metabolism of galactose, the major sugar found in milk. Incidence is 1 in 50,000. Symptoms include severe mental retardation, overwhelming systemic infections, failure to thrive, vomiting, liver disease, and cataracts. Untreated galactosemia is generally fatal. Treatment requires elimination of milk and milk products (all products containing lactose) from the diet.

G6PD Deficiency—G6PD deficiency is the most common genetic enzyme deficiency, occurring most often in tropical and subtropical Asia, tropical Africa, areas of the Mediterranean, the Middle East, and New Guinea. It can cause premature destruction of red blood cells (hemolytic anemia) when an affected individual is exposed to certain medications, chemicals, foods, or pollen. Severity of the condition is extremely variable. Treatment involves restricting exposure to pathogens that cause a reaction.

SICKLING HEMOGLOBINOPATHIES

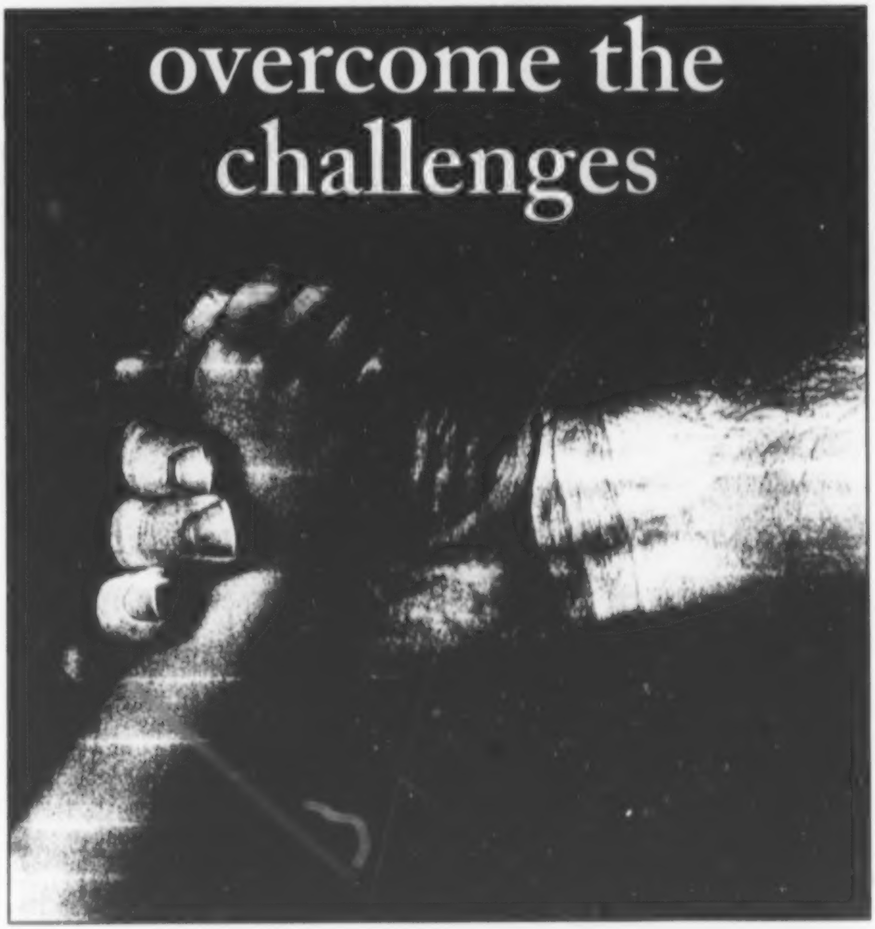
These are a group of disorders characterized by abnormal hemoglobin-chains: sickle-cell disease and thalassemia are two. Overall incidence of hemoglobinopathies in the US is 1 in 58,000. Sickle cell is most commonly found in African-Americans and has an incidence of about 1 in 600. Thalassemia is most likely to affect people with eastern Mediterranean (Greek, Arabic, Italian) or East Indian ancestry. Symptoms are lifelong hemolytic anemia, abnormally shaped blood cells leading to acute and chronic tissue damage, episodic vaso-occlusive crises, splenic sequestration, and sepsis. Ongoing therapy is penicillin prophylaxis and vigilant treatment of infections. Aggressive pain management, management of dehydration and acidosis, blood transfusions, and oxygen are all utilized for acute episodes. ■

***Theoretically detectable in the newborn period.**

MANAGING INCONTINENCE: Helping children learn about and overcome the challenges

In the first article of this special series on incontinence (published in last month's issue), Dr. Michael J. Solomon discussed the medical causes of and treatments for incontinence in children with disabilities. In this segment, we take a look at approaches—for both parents and children—to the day-to-day management of incontinence. Next month's segment will provide practical techniques for toilet training.

by Gale Jurasek



The consequences of incontinence can be devastating both for the child and his or her family. There are, however, many things that both parent and child can do to make the problem manageable.

Incontinence may take several forms. Some children may be completely unable to hold their urine at all times. Other children may have occasional difficulty, such as nocturnal enuresis (bedwetting), with "accidents" causing embarrassment and limiting normal activity (such as attending sleepovers, outings, or summer camp). Another side of incontinence is when children may feel the need to urinate, but their bladders are unable to voluntarily release the urine (called overflow incontinence).

The first step for parents is to recognize that their child may be having trouble achieving continence despite his or her efforts to do so. Dr. John Wiener, MD, Head of Pediatric Urology and Assistant Professor of Surgery and Pediatrics at Duke University Medical Center, Durham, North Carolina, and member of the advisory council of the National Association for Continence*, explains that bladder control is a function of both brain and muscle activity. "No one is truly able to control his or her bladder before the age of 18 months. It requires a certain cognitive ability to sense when the bladder is full, and muscle control to allow an individual to get to the toilet. Children learn to walk and talk before they learn to control their bladders." Usually around the

*See Resources at the end of this article for contact information.

Dr. John Wiener, MD

age of 3 or 4, a child will begin to voice concerns about incontinence. This is a signal that the child is prepared to begin learning management techniques. Dr. Wiener stresses that every child will reach this stage at his or her own pace. There is no set age.

Though helping their child achieve continence can be frustrating for parents, punishment is never an effective tool, and is often harmful. The child may simply have no ability to control the bladder. Cheryle B. Gartley, Founder and President of the Simon Foundation for Continence* (an organization dedicated solely to providing help and support for individuals with urinary incontinence) agrees. "It's just agony to hear about it—when all the punishment in the world is not going to change the situation."

Helping your child build self-esteem

Incontinence in a child with a disability, or in any child, will challenge his or her self-esteem. Parents are often faced with trying to help their child learn self-care techniques just at a time when their child's self-image is suffering. Self-image and self-esteem are two extremely difficult issues for children with incontinence, as well as for their families. The challenge begins when the child becomes aware that other children do not have this problem. Ms. Gartley points to one great stride in engaging children—or anyone—in the challenge of incontinence. "Three or four years ago, a large pharmaceutical company entered the market with a drug for urge incontinence (constantly feeling the need to empty the bladder). Instead of 'bladder-control incontinence,' or any of the other terms that have traditionally been used, they referred to the problem as 'overactive bladder.' Now, when I speak to some of my physician colleagues, they say, 'People are much more willing to come in and talk about their overactive bladder.' It's not stigmatizing."

At some point in a young child's life, awareness of his or her problem will dawn. At this point, Gartley suggests that parents broaden their child's perspective. First, make certain the child understands that the bladder problem is related to other physical challenges they have. Then, says Gartley, "Tell them there are lots of people—and other little boys and other little girls their age—who appear 'normal.' That same little child may go home each night to face his or her bedwetting problem." There is nothing, Gartley says, to be gained from focusing on the negative aspects of the situation. Those are things the child must live with. Instead, help a young child understand what is going on in his or her body, driving home the point that it is not the child's fault.

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A child may interpret lack of bladder control as still being a "baby." And that is the taunting they will encounter. Gartley recommends referring to the bladder as a muscle that can "misbehave"—and not only for the child. "Point out," she says, "that there are a lot of adults out there whose bladders are misbehaving." They can see this from the many adult incontinence products in the local drug store. Even a young child can understand the idea of the bladder as a muscle that contracts and relaxes, as when they make a fist. What they have is a muscle that misbehaves—just like for a lot of people, including grown ups. This lessens some of the perception of "all my friends are grown-up kids now, but I'm still a baby."

That parents feel responsible for causing their child's disability is, according to Gartley, often "the biggest issue" and damaging to everybody and everything. She emphatically says, "Put a second mortgage on the house, sell one of the cars, do whatever it takes to buy the mental healthcare that is needed. Because every single day that a parent looks at the world from that viewpoint is not only going to harm the parent, it's going to harm the family relationship, and it's going to harm the child." Support groups can be a great help.*

A positive attitude in a child results from a positive attitude in the parent. "Parents worrying too much and putting too much focus on the child's incontinence is detrimental," says Dr. Wiener. "A child with spina bifida or Down syndrome may not be continent with simple measures. Fretting about it is not going to make it better. Let the child be a child. While parents should certainly deal with the problem, they shouldn't focus on it so much that it interferes with the child having an otherwise normal childhood. Do things to help the child's self-esteem in terms of trying to find solutions. For example, if it makes a child feel better being in a Pull-Up, and it helps his or her self-esteem, that's great."

In addition, giving the child responsibility greatly helps the learning process. The management techniques a child learns will most likely be part of his or her daily routine for a lifetime. "Parents may feel guilty that their child has spina bifida, and they feel even worse that their child has incontinence. However, if the child has the ability, he or she needs to take responsibility for trying to be dry," Wiener asserts. "This may require effort on the child's part: for an older child, for example, it may mean helping do the laundry or cleaning up an accident. Approach it from the point of view of this is part of helping the child learn to take care of him or herself."

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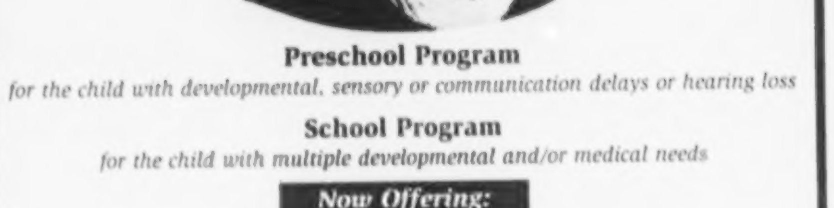

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"Parents should do everything they can to help their children understand that, yes, indeed, I have different challenges, but look how much ahead of the rest of the world I am because I can handle those challenges!"

First steps

Wiener suggests parents introduce a child with a disability or condition that causes incontinence to a potty just as they would any other child. "Get the child on the potty, have him spend time on the potty, help her understand what it is used for, and teach about normal bathroom habits. Often parents have their child remove his or her diaper and dump the stool in the toilet—that's where it goes. This introduces the child to regular toileting. Engaging the child in the effort is important—obviously, if the child has no interest, there's a low likelihood of success."

Some disabilities, such as spina bifida, can make bladder control impossible for children. Dr. Wiener suggests, "Parents can explain to their child that the disorder may mean they will not be able to control their bladder like other kids, but that trying is the only way to find out. If the child is not having success, and they truly want to be dry, talk to an expert, either a urologist or a neurologist."

Dealing with incontinence is often a matter of finding out what routine the child needs to follow, and then helping him or her learn to follow it. "We have ways of doing this (managing incontinence) that do not require surgery. Not everybody requires (intermittent) catheterization. There are so many simple measures that work."

Cheryle B. Gartley, President and Founder of the Simon Foundation for Continence.

Setting a schedule

The first thing Dr. Wiener teaches the children who come to him with incontinence problems is scheduled voiding. He describes his approach with an example. "Think of your bladder as a bucket. Your kidneys are making urine continuously, filling up your bladder. What happens if you try to walk around with a full bucket?" Engaged in the subject, children usually respond, "It's going to spill." Agreeing with them, Dr. Wiener suggests, "If you empty the bucket before it gets full, then you're less likely to spill."

He usually starts by having children work toward voiding every hour. With a feeling of success over that milestone, the child then can aim for every hour and a half, moving steadily toward every three hours. This process can take several weeks and varies for each child. It takes a lot of work on a parent's part and can often involve teachers and caregivers, as well. Sometimes, the process is helped by getting the child a wristwatch or keeping charts so that they can watch their progress. Dr. Wiener has found that some children benefit from keeping a chart by the toilet and checking off each time they "go." He adds, "If they can keep on schedule through the day, they receive a star or a sticker. If they can string together five to seven successful days, there is a reward (such as a new toy or video). Some call it bribery, but we call it positive reinforcement. The most important thing is to get the child on schedule."

It is important to remember, however, that this process is of a very personal nature. A child may be embarrassed if a parent or other adult keeps asking him or her in the presence of others if he or she needs to use the bathroom. Discretion is important for privacy and self-esteem.

Another technique for helping manage incontinence is Kegel (or pelvic-floor) exercises. Dr. Wiener explains that continence is a combination of the bladder staying full and the pelvic floor muscles holding urine in. Voiding occurs when the pelvic floor muscles relax and the bladder contracts. He continues, "It's hard to teach children how to contract and relax their pelvic-floor muscles, but it's often necessary." Sometimes this is taught using biofeedback by putting a sensor on the perineum. The perineum is the external surface of the tendon that runs between the anus and the genitals. The sensor will pick up the pelvic-floor muscle contracting and relaxing and depict it on a monitor so that children see and can learn how to contract that muscle. More important, says Dr. Wiener, "They learn to relax it, so they can urinate and empty their bladder completely. Many children have accidents when they don't completely empty their bladder—it fills up again too quickly."

Sometimes, Wiener reports, anticholinergic drugs such as oxybutynin are prescribed. These drugs relax the bladder muscle so it is less likely to contract and empty spontaneously. The bladder can hold more but the urge to urinate is reduced. The child may then be able to prolong the time between periods when the bladder needs to empty. The common side effects of these drugs are constipation, dry mouth, and flushing of the skin. These drugs may also decrease sweating, thereby reducing heat tolerance.

Self-catheterization

Some children have overflow incontinence, which is the opposite problem of an overactive bladder; that is, their bladders do not

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empty. When this is the case, they can learn to self-catheterize *(See EP August 2000 articles, "Incontinence—the Medical Story" and "Life Is so Much Easier" for a detailed description).* Some children can use a catheter intermittently (usually every four to six hours) to empty their bladders. For patients who catheterize but are not completely dry, Dr. Wiener suggests anticholinergic medications to allow the bladder to store more urine. "Sometimes, to tighten the bladder neck if urine is leaking, we will try alpha-adrenergic agonists: basically, cold medicine. These medicines, which act on the sinuses, also contract the urethra (the bladder neck)."

According to Gartley, learning to self-catheterize is an excellent way to build self-esteem in a child. She recommends that parents praise the child for learning such a skill. She notes that many adults who are taught self-catheterization prior to or following surgery are very challenged and frightened. "At Childrens Memorial (in Chicago), when I'm working with the pediatric urology group, there will be little 4-year-olds who self-catheterize saying 'Look at what I can do!' They're very proud of it. It's second nature to them, and that's something to be praised."

That adults have to self-catheterize, too, is important for building awareness in the child, says Gartley. If parents point out magazine ads on overactive bladders to their child, she says, "The child will start to think, 'Well, this is a pain in the neck, but it's also a skill that others can't do, and it's also me taking care of me.' Obviously, there's a lot of self-care these children can't do. But if this is one thing they can do, point it out to the child. Parents should do everything they can to help their children understand that, yes, indeed, I have different challenges, but look how much ahead of the rest of the world I am because I can handle those challenges! This is an opportunity to build self-esteem and combat the negative input he or she gets from society at large."

As in so many situations, particularly as children enter the teen years, they do not always do what is best for good health. "We often have trouble in teenagers who have been taught self-catheterization," Dr. Wiener reports. "Many of these patients have normal cognition and are in school. The kids who can walk have the hardest time because they look 'normal'—but their bladders still do not work properly. So they try to make the problem go away by stopping catheteri-

Nocturnal enuresis

Bedwetting—or nocturnal enuresis—affects 15 percent of all children around the age of five. For one percent of them, enuresis continues well into their teens. It can cause embarrassment for both the child and the parents—so much that many families will not seek help.

The cause of nocturnal enuresis is not known, although multiple factors are suspected. One theory is developmental delay—not globally, but in the specific part of the brain that, when the child is asleep, monitors the state of the bladder. Most children outgrow enuresis. For this to happen, the brain needs to be aware either that the bladder is full and it is time to wake up or, in the case of an overactive bladder that empties when it is only 60 to 70 percent full, that it can take on more and should not empty.

In terms of nocturnal enuresis management, Dr. Wiener advises that the first thing to look at is fluid intake. And, he stresses, "caffeine is out—whether it is in coffee, tea or soda. Caffeine is a diuretic—it increases urine output. For some children, eliminating caffeine greatly reduces trouble with enuresis." After three or four in the afternoon, Wiener suggests, a child with enuresis should avoid anything with caffeine. In addition, cut back on the amount of fluid at suppertime, and make sure the child voids before bedtime—"so they start the night with an empty bucket."

If restricting fluid intake does not work, there are some drugs that may help. The most common of these is desmopressin acetate, or DDAVP. This drug resembles a hormone (arginine vasopressin) that the brain secretes, which concentrates urine at night, thus reducing output. There is a theory that nocturnal enuresis is caused by insufficient secretion of this hormone. DDAVP is effective in about 60 to 75 percent of patients. When the drug is withdrawn, however, the majority of children do not remain continent overnight.

One of the best therapies, Wiener contends, is an enuresis alarm. A small, battery-operated device with a sensor, it is placed in the underwear. When it gets wet, a loud alarm sounds. "Sometimes the child will wake up; otherwise, parents need to get up with the alarm to get the child to the bathroom." Says Wiener, "Eventually the brain says, 'Aha, so this is how it's done.' In the long run, over half of those children using the alarm will be dry permanently. It's really their best chance for success." Wiener emphasizes that parents should be actively involved. They can help their child by keeping a chart to track progress and by using positive reinforcement, similar to that used in teaching scheduled voiding.

According to Dr. Wiener, "Treatment of enuresis or incontinence in general has a big impact on self-esteem, on performance in school, on everything." He warns, however, that too much attention to the child's problem will often encourage its use as a way of getting more attention. "If parents treat their child more as they would any child of that age, the child is going to function better."

zation. As some children try to be more 'normal,' they may often try to ignore or just deny their problem. They don't do the regimen they are supposed to."

To try to prevent this attitude toward catheterization from developing, Wiener recommends that parents be very open, letting the child be a willing participant in discussion of the process, and involving him or her rather than simply stating, "You have to do this." He advises, "Get the child's input from as early in life as possible so that incontinence management is a normal part of life." Frank and open discussion about urination and defecation from the early years on can help avoid creating an atmosphere of embarrassment, either for the child or the parent. "It's a normal part of our bodies," says Dr. Wiener, "Don't be afraid to talk about it. Once they learn the technique, it is usually nowhere near as big a deal as the child thought it would be. And once they start doing it, they realize the great benefit."

> *"Get the child's input from as early in life as possible so that incontinence management is a normal part of life."*

Some parent pointers

Every parent should talk to their child's teachers to assess their attitude toward bladder control accidents. Gartley says, "Doctors, nurses, and teachers all grew up on the same planet as we did, with the same stigmas and problems. Parents need to get in there and assess what their child is going to be dealing with. If it isn't going to be a pretty picture, they might ask for some changes."

Because these children are going to be receiving negative input, Gartley suggests countering it with positive action to balance out all of the "what's wrong with you?" attitudes. Gartley suggests helping the child discover at an early age the positive ways in which they are unique, and recording their successes in pictures and scrapbooks. Then, when someone asks, "What's wrong with you?" the child will be able to say, "Well, there's a lot that's right with me. For example…"

According to Gartley, the "what's wrong with you?" messages occur constantly and early in a child's life. It is important for

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children to become aware of the type of language that is being used and to recognize that the attitude that causes them is the other person's problem. The other person has a lot that is "wrong" with them. But, she continues, "*They* don't get asked about it because it is either not visible or is socially acceptable (like eyeglasses or braces on their teeth). What is important is to recognize that this type of input is present and to decide what you're going to do for yourself to bring other input into your life." Gartley acknowledges that there are many disability advocates who feel that they should not have to do more just because they are disabled. She says that doing something positive is not the same thing as being obligated to 'prove yourself.' "I see this as a self-choice to begin putting good things into your life; and I think everybody can do that for their own self esteem."■

Resources

Both of these organizations can refer parents and professionals to continence support groups.

The Simon Foundation for Continence

Call (800) 23-SIMON (800-237-4666) for a free information packet

The Simon Foundation also offers many resources, including their book "Managing Incontinence: A Guide to Living With Loss of Bladder Control."

Web site: http://www.simonfoundation.org

E-mail: simoninfo@simonfoundation.org

The National Association for Continence

(800) 252-3337

Web site http://www.nafc.org

E-mail: lloudon@nafc.org

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Circle #19

1045

Parents as Partners in The Medical Home:

What Should Medical Facilities Look Like?

Contributors: David Hirsch, MD, FAAP, Diana Frieberg, Mae Moore, **Phoenix Pediatrics, Ltd.**; Judie Walker, **Raising Special Kids**

Brian Jenkins is an 8-year-old with spina bifida who uses a wheelchair. Every week his mom takes him to physical therapy. Unfortunately, the agency is located on the second floor of a building that has no elevator.

Brad Johnson is the father of a 5-year-old girl with multiple disabilities. He takes her to all of her primary care and specialty care doctor appointments. Unfortunately, none of the facilities has a "family" bathroom with a changing table. There is no place for him to take care of his daughter's personal needs.

Jodie Wheeler's 5-year-old daughter uses a ventilator. When they travel she takes along a battery-run unit. One visit to the doctor's office took much longer than expected. The ventilator battery wore down before she saw the doctor. Unfortunately, the doctor's office did not have a convenient outlet in the examination room for recharging the battery.

Bobbie Geste, a 200-pound 16-year-old male, uses a wheelchair as a result of severe traumatic brain injury. His wheelchair is too big to fit on the scale in his pediatrician's office. He is too heavy to lift, and he cannot stand on a regular scale. Nonetheless, information about his weight is critical for evaluating his dietary intake and medical status.

The pediatrician's office has no tray toys for 6-year-old Anthony to use in his wheelchair. He becomes restless and agitated while waiting for his mom to pay the bill.

Partners In The
Medical Home Project

The physical environments of healthcare facilities take on special importance for families and children with special healthcare needs considering that most require four to eight times more healthcare services than do other children according to a 1994 study by the Institute for Family-Centered Care. Visits to doctor or clinic offices with a child with special healthcare needs can be a physically taxing, stressful experience. It can involve lugging oxygen, opening a door and securing it long enough to get a wheelchair through, carrying all the necessary medical supplies, and/or finding a private spot to change a diaper. On average, waiting time ranges from 35 minutes at physicians' offices and hospital emergency departments to 52 minutes in hospital clinics. Add the additional time necessary to care for multiple issues, referrals to specialists, and a stop at the pharmacy. Frequent and lengthy visits to healthcare facilities are an inevitable part of caring for children with special healthcare needs. Access to basic necessities and conveniences can make an enormous difference to families and children. By taking these needs into account, health facilities can alleviate some of the stress and allow the families to concentrate on more important issues.

Defining features of healthcare facilities

Our research team, made up of parents and

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An accessible and friendly physical environment at a healthcare facility is an important feature for families with children with special needs. Shown here is the billing area at Phoenix Pediatrics, Ltd.

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Having toys and games available at the healthcare facility helps create a positive atmosphere for families and children.

professionals, examined the extent to which health organizations serving families and children with special health needs provide the physical facilities they need. (See *EP Aug. 2000* for details on the team and its function.) The team met monthly in its study of healthcare facilities for special children. They reviewed the Americans with Disabilities Act (ADA), architects' perspectives on medical facilities for children as well as research that investigated the impact of the physical environment on children and adults' health status.

Americans with Disabilities Act. The ADA recognizes the importance of the physical environment for people with disabilities. The Act mandates that people with disabilities be provided means to access buildings (e.g., special, wide "handicapped" parking spaces: ramps; good lighting; navigable corridors; large elevators with low buttons). The ADA further stipulates criteria for inside buildings, including space to park a wheelchair, large countertops at wheelchair level, outlets or extensions for medical equipment, bathrooms with a bench in changing areas for siblings and materials and sinks and towel racks lowered on walls, as well as an exam table at appropriate height.

In spite of the ADA, parents on our team related many problems accessing and using health facilities, as noted in the examples provided above. Although the ADA has had a significant impact in making more buildings accessible to adults with physical disabilities, the needs of families and children with special needs has not been studied and remain largely undefined. As a result, parents have little recourse when trying to navigate buildings with wheelchairs, oxygen tanks, doorstops, feeding pumps, suction machines, and ventilators, not to mention their children.

Architects' definition of physical environments. A number of architects specialize in designing healthcare facilities for populations with special needs. Architects define the physical environment broadly to include: 1) space and function (e.g., crowding, layout, equipment, furnishings); 2) ambient conditions (e.g., temperature, air quality, noise, music, odor, colors, lighting, textures); and 3) signs, symbols, and artifacts (e.g., signage: "wayfinding" such as arrows or footprints on the floor; style of décor; and the presence of toys).

Architects routinely consult with clients to determine physical space needs as part of designing facilities. In the health field, architects have traditionally worked with medical staff and administrators. Recent studies of consumer satisfaction, however, cite physical features of the health facility more frequently than any other determinant of satisfaction and service quality. In response, medical staffs have become more inclined to include input from consumers when working with architects. Because children with special healthcare needs represent a newly emerging and small set of consumers, most facilities have been built without taking their needs into account.

The impact of the physical environment on health status

The physical features of health facilities have a significant impact on the effectiveness of medical care, as well as consumer satisfaction. For adults, the setting affects choice of physician, compliance with health regimens, disclosure of information, and requests for pain medication. For children, the effects of the environment have been studied mainly in hospital settings. The setting influences length of hospital stay, the amount of time parents spend with their children, the number of volunteers, and levels of hospital fundraising. Parents of children with special healthcare needs surveyed at the Egg Harbor *ABC's of Managed Care Conference* in 1995 identified the physical environment as one of seven indicators of quality healthcare.

The team defines a quality physical environment

The team's extensive review of the literature did not locate any sources that examined whether the offices of healthcare providers serving children with special healthcare needs are in compliance with the ADA or meet standards set by architects. The team decided to address the issue by generating a list of the characteristics of health facilities that are essential for meeting their needs. The goal was to specify features that meet basic needs, reduce family stress, and create a positive environment for families. The team was careful to consider how diverse medical conditions, cognitive and physical development, age, and behavior might affect needs. The team was mindful not to include features that agencies would find unreasonable. The team used the characteristics to create a Physical Environment Survey.

The Physical Environment Survey

The Physical Environment Survey evaluates: a) parking lot and building entry; b) billing and reception area; c) waiting area; and the d) examination room (Table 1 presents the Physical Environment Survey). The left-hand side of the survey indicates whether the ADA mandates the feature (yes/no). Respondents rate whether the feature is present (1=not present, 2=present, but not adequate, 3=present and adequate, 4=outstanding) and its importance (1=essential, 2=not essential, 3=not applicable).

Team evaluates physical environment of health-related facilities

The team used the Physical Environment Survey to evaluate 60 healthcare facilities. The team evaluated 21 pediatrician offices, 15 clinics, 11 dentists, and 13 other health-related sites (i.e., medical equipment and supply facilities). The analysis examined whether facilities met ADA requirements, the needs of children at different ages (1-5 years, 6-10, 11-15, 16+ years) and ambulatory status (ambulatory, non-ambulatory), and compared the adequacy of the different types of facilities.

ADA compliance. Fifteen items on the

Survey are mandated by the ADA. Parents' ratings of these items indicate that the average for ADA compliance across the four sites was slightly above 2.0—meaning items were present, but not adequate. Each site was minimally compliant with ADA requirements. Pediatricians' offices were rated slightly more compliant than the other facilities. One dental office and two clinics were rated highly compliant. The dental office has spacious, uncrowded waiting areas that are accessible to wheelchairs and other devices. Signs are posted that inform families of the dentist's commitment to children with disabilities. Parents have access to a gender-free bathroom in which wide changing space is available. The two highly rated clinics, located in recently remodeled hospitals, provide ample space, phones for parents, and numerous electrical outlets.

Age. Children were divided into 4 age groups (1-5, 6-10, 11-15, 16+ years) to assess whether facilities are more likely to meet the needs of patients at different ages. Families made an average of 2 visits per month to the various facilities. There were no differences based on age, but parents of the 16+ year olds rated facilities higher than parents of 6 to 10-year-olds. Nonetheless, none of the ratings reach the "present and adequate" ("3") level.

Ambulatory status. Thirty-one children were ambulatory and 29 were non-ambulatory. Ambulatory children were more likely to visit pediatricians' offices, whereas non-ambulatory children were more likely to visit clinics and other medical-related offices. Families of ambulatory children rated exam rooms and corridors as more adequate than families of children who were non-ambulatory. Again, none of the ratings reached the "present and adequate" ("3") level.

Type of healthcare facility. The ratings were similar for clinics and pediatricians' offices, although pediatricians' offices were rated slightly more compliant. Examination rooms in pediatricians' offices were rated somewhat higher than examination rooms in dental offices and clinics. Building Entry was the only category to exceed the 2+ level of "present but not adequate," but still fell short of the "present and adequate" ("3") level.

Putting it all into perspective

Families and children with special healthcare needs represent a growing segment of our population. Advances in medical science and technology have created new pioneers: families striving to normalize the lives of their chil-

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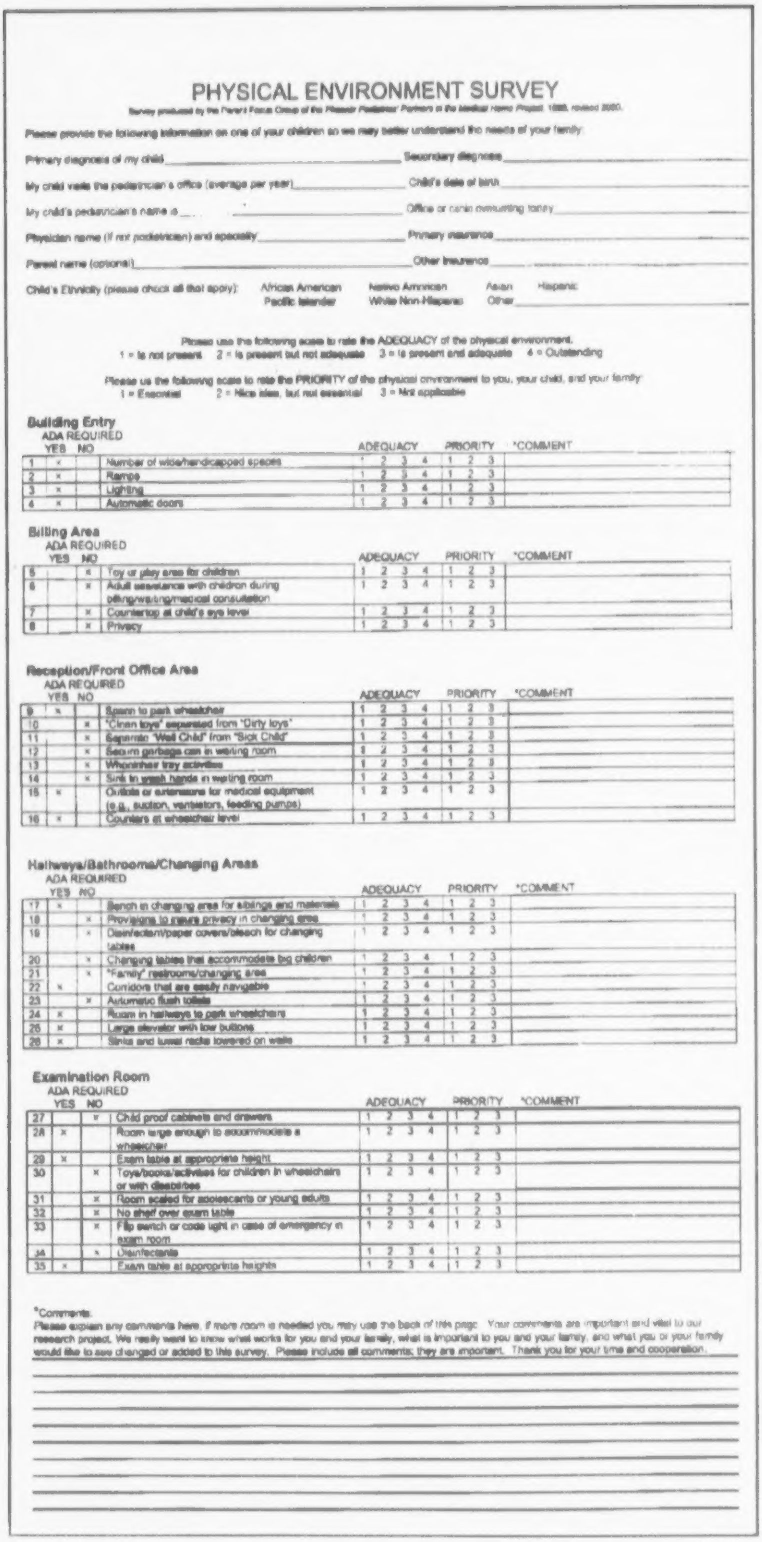

PHYSICAL ENVIRONMENT SURVEY

Survey produced by the Parent Focus Group of the Phoenix Pediatric Partners in the Medical Home Project, 1999, revised 2000.

Please provide the following information on one of your children so we may better understand the needs of your family:

Primary diagnosis of my child ________ Secondary diagnosis ________

My child visits the pediatrician's office (average per year) ________ Child's date of birth ________

My child's pediatrician's name is ________ Office or clinic completing survey ________

Physician name (if not pediatrician) and specialty ________ Primary insurance ________

Parent name (optional) ________ Other insurance ________

Child's Ethnicity (please check all that apply): African American Native American Asian Hispanic Pacific Islander White Non-Hispanic Other ________

Please use the following scale to rate the ADEQUACY of the physical environment.
1 = Is not present 2 = Is present but not adequate 3 = Is present and adequate 4 = Outstanding

Please us the following scale to rate the PRIORITY of the physical environment to you, your child, and your family:
1 = Essential 2 = Nice idea, but not essential 3 = Not applicable

Building Entry

	ADA REQUIRED YES	NO		ADEQUACY	PRIORITY	*COMMENT
1	×		Number of wide/handicapped spaces	1 2 3 4	1 2 3	
2	×		Ramps	1 2 3 4	1 2 3	
3	×		Lighting	1 2 3 4	1 2 3	
4	×		Automatic doors	1 2 3 4	1 2 3	

Billing Area

	ADA REQUIRED YES	NO		ADEQUACY	PRIORITY	*COMMENT
5		×	Toy or play area for children	1 2 3 4	1 2 3	
6		×	Adult assistance with children during billing/waiting/medical consultation	1 2 3 4	1 2 3	
7		×	Countertop at child's eye level	1 2 3 4	1 2 3	
8		×	Privacy	1 2 3 4	1 2 3	

Reception/Front Office Area

	ADA REQUIRED YES	NO		ADEQUACY	PRIORITY	*COMMENT
9	×		Space to park wheelchair	1 2 3 4	1 2 3	
10		×	"Clean toys" separated from "Dirty toys"	1 2 3 4	1 2 3	
11		×	Separate "Well Child" from "Sick Child"	1 2 3 4	1 2 3	
12		×	Secure garbage can in waiting room	1 2 3 4	1 2 3	
13		×	Wheelchair tray activities	1 2 3 4	1 2 3	
14		×	Sink to wash hands in waiting room	1 2 3 4	1 2 3	
15	×		Outlets or extensions for medical equipment (e.g., suction, ventilators, feeding pumps)	1 2 3 4	1 2 3	
16	×		Counters at wheelchair level	1 2 3 4	1 2 3	

Hallways/Bathrooms/Changing Areas

	ADA REQUIRED YES	NO		ADEQUACY	PRIORITY	*COMMENT
17	×		Bench in changing area for siblings and materials	1 2 3 4	1 2 3	
18		×	Provisions to insure privacy in changing area	1 2 3 4	1 2 3	
19		×	Disinfectant/paper covers/bleach for changing tables	1 2 3 4	1 2 3	
20		×	Changing tables that accommodate big children	1 2 3 4	1 2 3	
21		×	"Family" restrooms/changing area	1 2 3 4	1 2 3	
22	×		Corridors that are easily navigable	1 2 3 4	1 2 3	
23		×	Automatic flush toilets	1 2 3 4	1 2 3	
24	×		Room in hallways to park wheelchairs	1 2 3 4	1 2 3	
25	×		Large elevator with low buttons	1 2 3 4	1 2 3	
26	×		Sinks and towel racks lowered on walls	1 2 3 4	1 2 3	

Examination Room

	ADA REQUIRED YES	NO		ADEQUACY	PRIORITY	*COMMENT
27		×	Child proof cabinets and drawers	1 2 3 4	1 2 3	
28	×		Room large enough to accommodate a wheelchair	1 2 3 4	1 2 3	
29	×		Exam table at appropriate height	1 2 3 4	1 2 3	
30		×	Toys/books/activities for children in wheelchairs or with disabilities	1 2 3 4	1 2 3	
31		×	Room scaled for adolescents or young adults	1 2 3 4	1 2 3	
32		×	No shelf over exam table	1 2 3 4	1 2 3	
33		×	Flip switch or code light in case of emergency in exam room	1 2 3 4	1 2 3	
34		×	Disinfectants	1 2 3 4	1 2 3	
35	×		Exam table at appropriate heights	1 2 3 4	1 2 3	

*Comments:
Please explain any comments here. If more room is needed you may use the back of this page. Your comments are important and vital to our research project. We really want to know what works for you and your family, what is important to you and your family, and what you or your family would like to see changed or added to this survey. Please include all comments; they are important. Thank you for your time and cooperation.

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dren with special healthcare needs in mainstream society. In order to help these families realize their dreams and aspirations for their children, professionals and policy makers need to be aware of what these needs are. In this project, parents contributed their expertise and experience to defining the physical environment of healthcare facilities for children with special healthcare needs. Although there were a few notable exceptions, parents' evaluations indicate that families' needs are not being adequately met by the very agencies that are responsible for providing services to their children. Irrespective of the child's age or ambulatory status, few of the facilities were rated 'present and adequate' in any of the categories.

We recognize that many of the facilities serving these children were built years ago, at a time when children with serious, chronic, and complex health and physical problems were much less likely to survive and be served by the institution. Many who did survive were placed in segregated institutions. But times have changed. The federal government has recognized the changes with legislation signaling commitment to full inclusion of people with disabilities in American society—at home, in school, and in the work place.

There is no doubt that the ADA has made a significant impact on the lives of many persons with disabilities. Nonetheless, insufficient attention has been given to the physical attributes of healthcare facilities serving children with special healthcare needs. Those facilities serving families participating in the survey were found to be minimally in compliance with ADA, and few of the 60 facilities were rated as adequate.

The goal of participatory research is to produce solutions to everyday problems faced by families. When the team learned that an agency serving children in wheelchairs was located on the second floor of a building with no elevators, the team decided to take action. We sent a letter describing the team's work on physical environments for children with special needs, informed the agency of its lack of compliance with the ADA, and included a copy of the Physical Environment Survey. Parents requested that the agency indicate its plans for alleviating the problem. The agency responded rapidly and politely, but claimed to be in compliance. However, less than a year later, the agency moved to an office on the first floor. Other medical offices became aware of the team's work and also began making changes, such as tissues, a dressing table in a bathroom, special help opening the door. As the astronaut said, "That's one small step for man, one giant leap for mankind."

Families have to be prepared to tote the medical equipment and aids necessary for their children to participate in community events. Nonetheless, we urge parents to use the Physical Environment Survey to become more aware of the degree to which their communities are meeting their needs. The ADA's criteria should be applied to children as well as adults. Parents can use the results of our team's work to educate the facilities that serve them. We believe that like the professional members of our team, many healthcare providers are not aware of the degree to which facilities are not meeting the physical environment needs of families. No doubt there is strength in numbers. Healthcare providers may be more likely to respond to letters from organizations serving children with special needs. Based on our experience, healthcare providers responded positively when informed about families' needs. We also hope that other healthcare providers will use the Physical Environment Survey to self-evaluate and change. ■

Acknowledgement

We gratefully acknowledge the contributions of parents in the Improving Managed Care for Children with Chronic healthcare Needs Project. The study would not have been possible without the participation of Sharon Atwood, Elli Bogden, Lisa Carlson, Sherry Charlot, Janet Churchward, Brad Geeck, John Gooch, Velma Leftwich, Jackie Marchosky, Angela Moberg, Mae Moore, Sandra Partker, Aura Rubin, Bonnie Rubio, Leah Vincent, Darlene Watkins, Julie Webb, and Martha Young.

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To participate in the Physical Environment Survey: e-mail the authors at ppmedhome-@aol.com or call Dr. Burstein's office at (480) 965-8619. A copy of the Survey can also be found on EP's Web site: http://www.eparent.com.

Karen Burstein, PhD, and Tanis Bryan, PhD, both of the University of Arizona, are Co-principal Investigators for the Medical Home Project Team.

As a parent of a child with special healthcare needs and former CEO of a children's rehabilitation facility, Dr. Burstein brings expertise on the problems of families and children as well as research design to the team.

Dr. Bryan brings extensive knowledge and experience in conducting community-based investigations to the team.

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Circle #57

familiar faces

LEAH

Leah Navarre Phillips,7, is a happy camper! Born 3 months premature with cerebral palsy, Leah loves to use her walker to skate and shop at the mall. Leah was an honor student in her first grade class. She loves swimming and helping her dad work around the house. Leah lives with her parents, Sue and James, near New Orleans, LA.

BOBBY & DANIELLE

Bobby Grimes, 9, and his cousin, **Danielle Forston**, 13, have fun together! Bobby has cerebral palsy, GERD (gastroesophageal reflux disease), and a slight visual impairment. He likes to sit on his front porch and watch the horses and cows in his yard. He also enjoys listening to music and being with his family. He thinks riding the bus to school is fun, and so is therapy with his teachers. Bobby and his brother J.R., 19, live with their parents, Keith and Mary, in Georgetown, FL.

DANIEL

Daniel Licht, 6, is in the swim of things! Daniel has fibrodysplasia ossificans progressiva (also called FOP, it is a rare genetic disorder that causes bone to form in the body's healthy tissues.) According to his mom, Jeri, Daniel is a regular little boy who loves playing with his trucks, tools, and friends. He attends school with a full-time aide. Daniel lives with his mom and his dad, Peter, in Scarsdale, NY.

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Would you like to share a favorite candid snapshot or slide of your child and/or family with other readers of EXCEPTIONAL PARENT? Send it to: Readers' Photos, *EXCEPTIONAL PARENT*, 555 Kinderkamack Road, Oradell, NJ 07649-1517. (Please do not send originals or "one-of-a-kinds" as we regret that **photos cannot be**

DEMI & NADIA

Demi Marie, 4, and **Nadia Fanaras**, 11 months, hang out on the couch.

Demi has spastic quadriplegic cerebral palsy. She attends preschool and receives physical and occupational therapies, and has computer play. According to her mom, Maria, Demi is an extremely happy child and enjoys watching Rosie O'Donnell, televison chef Emeril Lagasse, and Sesame Street. The two sisters live with their mom and dad, Angelo, in Riverview, MI.

ALYSIA

Alysia Hartley, 5, is pretty as a picture! Alysia was born with a port-wine-stain birthmark and she also has bilateral Sturge-Weber Syndrome (a disorder characterized by excessive blood vessel growth, accumulations of calcium inside the brain, as well as seizures). Alysia loves the outdoors, being cuddled, and listening to music. She attends a special preschool and will start kindergarten next year. Alysia lives in British Columbia, Canada, with her parents, Leea and Karl, and her little brother Kyle, 3 months.

APRIL

April Williams, 9, flashes her smile! April has cerebral palsy and is legally blind. She receives physical, speech, occupational, and visual therapies at Westview Elementary School in Petersburg, VA. She enjoys going to school, listening to music, and watching cartoons. April lives with her mom, Monique, and sister, Sherell, 13, in Petersburg, VA.

---

returned.) On a separate sheet of paper, write your child's full name, age at the time the photo was taken, address and daytime phone number. Please identify everyone in the photo. If you like, you can also write a few sentences about your child. Then look for a familiar face in an upcoming issue!

The Special Needs III

BABY JOGGER
Rolls easily over any terrain • Folds easily
5-ppint harness • Quick-release wheels
We are happy to custom fit a stroller for your child!
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DMP
DURALINE MEDICAL PRODUCTS, INC.
[illegible]
[illegible]

Circle #41

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1. **Simply log onto our web site, www.eparent.com.**
2. **Click on the "free information" icon.**
3. **Request your information (select advertiser name, circle number and product type).**

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2. Circle the numbers on the Reply Card that correspond to the companies or products about which you would like to receive free literature.
3. Fill in your name and address on the card and mail the postage-paid card. You will receive free literature from each company for which you circled a number.
4. If both Reply Cards have been removed from this issue, just call or write to the companies directly.
   Be sure to tell them you saw their ad in EXCEPTIONAL PARENT!

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Exceptional Parent

September 2000

Please answer the following questions.

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☐ Yes ☐ No (If no, please visit our web site at www.eparent.com.)

Name ______________________________

Facility ______________________________

Address ______________________________

____

City ________________ State _____ Zip ________

Phone ________________ Fax ________________

B. Are you the PARENT or MEMBER OF THE FAMILY of a child or young adult with a disability or special health care need? 1☐ Yes 2☐ No

Free product & service information order card*

FAX this card to 413-637-4343 for quicker response

C. Are you a HEALTH CARE PROFESSIONAL involved in the care of children or young adults with disabilities or special health care needs? 3☐ Yes 4☐ No

If Yes, are you a: 5☐ Physician 6☐ RN 7☐ Physical Therapist 8☐ Occupational Therapist 9☐ Speech Pathologist; Audiologist 10☐ Other (please indicate) ________________

D. Are you an EDUCATOR? 11☐ Yes 12☐ No

If Yes, are you a: 13☐ Special Ed Teacher 14☐ Regular Ed Teacher 15☐ Admin/Dir 16☐ Other (please indicate) ________________

E. Do you buy or influence the purchase of products or services for the care or development of children with disabilities? 17☐ Yes 18☐ No

If yes, please explain ________________

F. Have you ever bought or recommended a product or service you saw advertised in ***Exceptional Parent***? 19☐ Yes 20☐ No

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Exceptional Parent

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Free product & service information order card*

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Center for Conductive Education and Hyperbaric Oxygen Therapy
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www.abilitycamp.com
Circle # 16
See our ad on page 120

Arkansas

Easy K Ranch
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Sagie, AR 72573
(870) 368-7444
Fax: (870) 368-7444
e-mail:shirlkell7928@excite.com
www.txrtech.com/easyk
Circle # 43
See our ad on page 112

California

The Bridge School
545 Eucalyptus Avenue
Hillsborough, CA 94010
(650) 696-7295 (650) 342-7598
www.bridgeschool.org
The Bridge School serves individuals who use AAC and AT. We operate a K-8 school program as well as many outreach projects including Building Bridges Camp.

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PO Box 697
Breckenridge, CO 80424
(800) 383-BOEC
Fax: (970) 453-4676
Year round adventures for all abilities. Programs include: Wilderness, Adaptive Skiing, Professional Challenge.
www.boec.org
e-mail: boec@boec.org

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Our community-based education and residential programs provide students with multiple disabilities every opportunity to reach their highest potential
www.ciboakhill.org

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Fax: (203) 380-1190
e-mail: feroleto.child.dev@snet.net
Providing education and therapeutic day programs for children, 0-21 with multiple medical/developmental needs.
Circle # 94
See our ad on page 102

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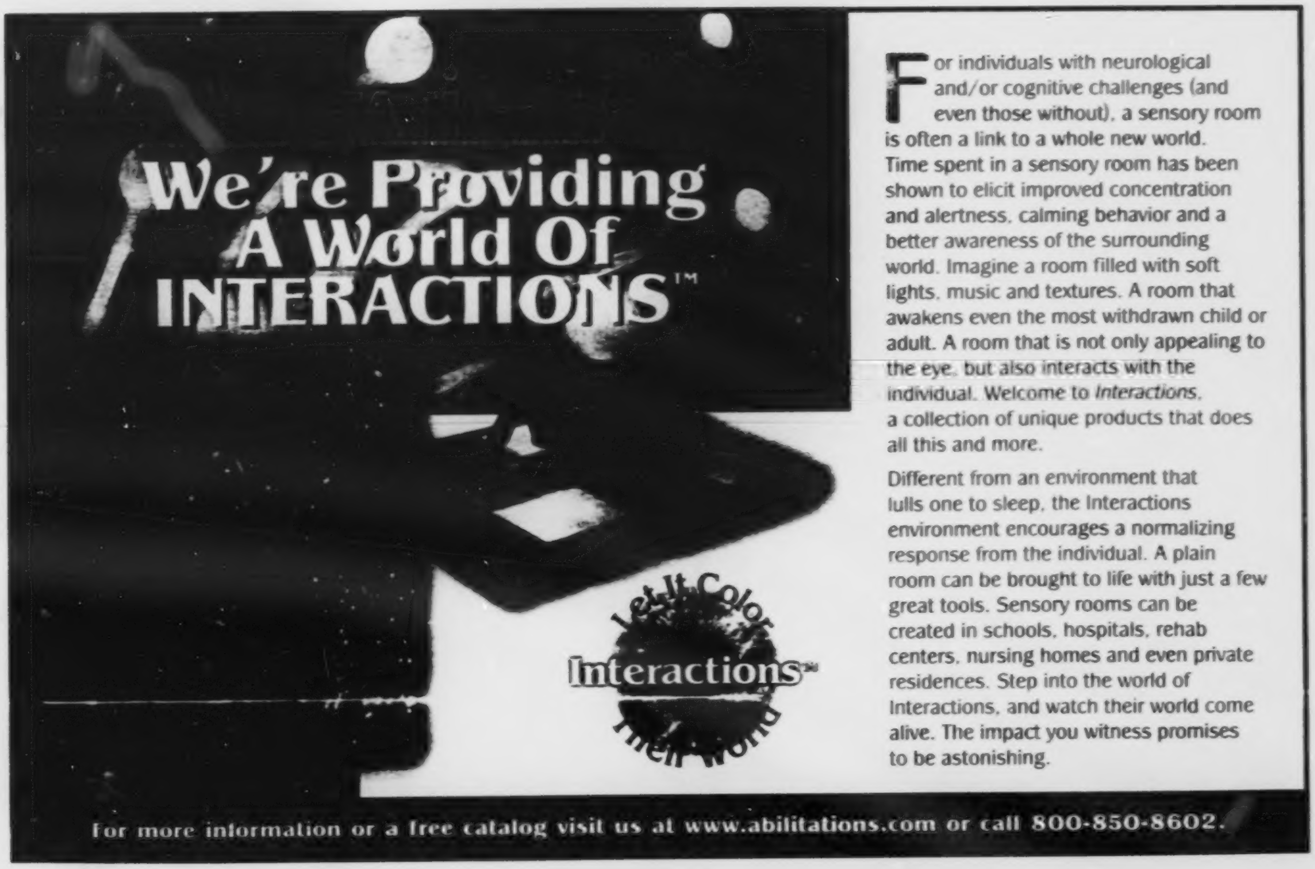
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345 Fortune Boulevard • Milford, MA 01757 • 508.478.2631
Serving students with developmental, medical and behavioral needs since 1981.

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Children's Care Hospital & School
2501 West 26th Street
Sioux Falls, SD 57105-2498
(605) 782-2300 or (800) 584-9294

Circle #28

CAMPHILL SPECIAL SCHOOL
Imagine the Best...
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- school & residential program (ages 4 - 19); pre-vocational program -openings for Fall '99; also for Integrated Kindergarten-
- wide variety of therapies; on-campus medical care staff & facility
- cultural activities-music, art, drama, festivals
- beautiful homes with permanent house-parent families
- Camphill Curative Education Seminar

1784 Fairview Road, Glenmoore, PA 19343
610-469-9236; Fax: 610-469-9758; e-mail: BvrRn@aol.com
website: http://ourworld.compuserve.com/homepages/camphill

Circle #27

continued from page 117

Delaware

The Mary Campbell Center Children-Youth Program
4641 Weldin Road
Wilmington, DE 19803
(302) 762-6025
Fax: (302) 762-4206
Quality social and recreational programs for youth with special needs and their siblings ages 3-21.

Florida

Miami Children's Hospital 15th Annual Ventilation Assisted Children's Camp (VACC)
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Miami, Fl 33155
(305) 662-VACC (8222)
Fax: (305) 663-8417
www.bela.florentin@ mch.com

The Duvall Home
Presbyterian Special Services, Inc.
3395 Grand Avenue
P.O. Box 220036
Glenwood, FL 32722
(904) 734-2874 (888) 445-4722
e-mail: cuvall@intersrv.com
Circle # 42
See our ad on page 122

Georgia

Annandale Village
3500 Annandale Lane
Suwanee, GA 30024
(770) 945-8381
Fax: (770) 945-8693
www.annandale.org
Full residential and day programs paid vocational training, job placement, recreational activities, case mgt., creative and performing arts, meals & counseling.
Circle # 19
See our ad on page 106

Illinois

The Hope School
50 Hazel Lane
P.O. Box 5810
Springfield, IL 62705
(217) 585-KIDS (5437)
Fax: (217) 786-3356

Iowa

Easter Seals Iowa
PO Box 4002
Des Moines, IA 50333
essia@netins.net
Serving individuals with disabilities. For CARF-accredited career training, call (515) 274-1529. For summer ACA-accredited camping, year-round respite, call (515) 289-1933.

[illegible]

Heartspring
8700 East 29th Street N.
Wichita, KS 67226
(800) 835-1043
Fax: (316) 634-0555
Our new campus provides a positive, practical environment for multidisciplinary programs that include education, life skills, communication, and behavior management. We serve children ages 5-21 with multiple disabilities.
www.heartspring.org
Circle # 55
See our ad on page 61

Kentucky

Stewart Home School
4200 Lawrenceburg Road Dept. B
Frankfort, KY 40601
(502) 227-4821
Fax: (502) 227-3013
www.stewarthome.com
Circle # 93
See our ad on page 56

Louisiana

St. Michael Special School
1522 Chippewa
New Orleans, LA 70130
(504) 524-7285
Fax: (504) 524-5883

Maryland

Benedictine Programs & Services
14299 Benedictine Lane
Ridgely, MD 21660
(410) 634-2112
Fax: (410) 634-2640
www.benschool.com
Circle # 24
See our ad on page 124

LISTING OF SCHOOLS, CAMPS, & RESIDENCES

Massachusetts

Berkshire Meadows
249 N. Plain Road
Housatonic, MA 02136
(413) 528-2523
Fax: (413) 528-0293
For people of all ages with severe developmental delay. They may be medically involved. We offer comprehensive and integrated medical residential and educational services. All therapeutic services are included.
www.berkshiremeadows.org
Circle # 25
See our ad on page 123

Boston Higashi School
800 North Main St.
Randolph, MA 02368
(781) 961-0800, ext. 109
Fax: (781) 961-3466
www.bostonhigashi.org
The International Program Serving Individuals with Autism. Affiliate Musashino Higashi Gakuen, Japan

Cardinal Cushing Center
400 Washington Street
Hanover, MA 02339
(781) 829-1205
Fax: (781) 826-1559
http://www.coletta.org

Cotting School
453 Concord Ave
Lexington, MA 02421
(781) 862-7323
Fax: (781) 861-1179
http://www.cotting.org
Circle # 35
See our ad on page 122

Evergreen Center
345 Fortune Blvd.
Milford, MA 01757
(508) 478-2631
Fax: (508) 634-3251
www.evergreenctr.org
Circle # 45
See our ad on page 118

IDDI, Crystal Springs School
38 Narrows Road
Assonet, MA 02702
(800) 840-8087 Ext. 434
Fax: (508) 644-3101 Ext. 372
e-mail: Css372@aol.com
Circle # 37
See our ad on page 124

New England Villages
664 School Street
Pembroke, MA 02359
(781) 293-5461
Fax: (781) 294-8385
e-mail: info@newenglandvillage.org
See our ad on page 64

continued on page 120

To Appear in *EXCEPTIONAL PARENT's*
Listing of Schools, Camps & Residences,
Contact Barbara Nastro at (908) 543-6366

National Association of Private Schools for Exceptional Children

NAPSEC is a nonprofit association whose mission is to ensure access for individuals to private special education as a vital component of the continuum of appropriate placements and services in American education.

National Representation
NAPSEC advocates for the rights of individuals with disabilities and their families.

Free Referral Service
NAPSEC provides information on potential placement options to parents and professionals who need an appropriate private special education and/or therapeutic setting for their child, family member, or client.

Nationwide Membership
NAPSEC represents private special education facilities throughout the U.S., by providing a wide array of membership services.

The National Association of Private Schools for Exceptional Children
NAPSEC
Serving Individuals with Disabilities and Their Families Since 1971

For additional information, contact:

Sherry L. Kolbe, Executive Director & CEO
NAPSEC, 1522 K Street, NW, Suite 1032, Washington, DC 20005
Phone: 202-408-3338 Fax: 202-408-3340 E-mail: napsec@aol.com Web Site: www.napsec.com

CHILEDA INSTITUTE

Educators for youth with developmental disabilities. Residential treatment center provides complete training & intensive therapy for children with severe mental & physical disabilities, closed head injuries & challenging behaviors. Founded 1973.

- Intensive
- Progressive
- Specialized

founded in 1973

Chileda Institute
1020 Mississippi Street • La Crosse, WI 54601
608-782-6480 • Fax: 608-782-6482
Web site: www.chileda.org

Circle #31

Ability Camp Inc.

Center for Conductive Education
& Hyperbaric Oxygen Therapy

We are a year round facility helping children with Cerebral Palsy. Our 120 & 145hr Conductive Education programs help children learn new skills, motivate, build confidence and become more independent. We also provide Hyperbaric Oxygen Therapy as a stand alone treatment or combined with our Conductive Education programs.

For information or to receive a free video, call:
1-800-442-6992 or www.abilitycamp.com

Circle #16

Our Unusual Crafts/Gardening Program Provides

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The Lukas Community
60 miles northwest of Boston near Peterborough, NH
Call (603) 878-4796
Visit our web site at www.mv.com/org/lukas/

Circle #68

continued from page 119

Riverbrook Residence, Inc.
4 Ice Glen Road, P.O. Box 478
Stockbridge, MA 01262
(413) 298-4926
www.riverbrook.org

The Ledges
P.O. Box 38
Hopedale, MA 01747-0038
(508) 473-6520
Fax: (508) 478-3054
A residential and educational center for developmentally disabled adults, aged 18 and older. Offers both campus style and community-based housing.

The New England Center for Children
33 Turnpike Road
Southboro, MA 01772
(508) 481-1015
Fax: (508) 485-3421
State of the art day/residential school and group homes for children with autism, PDD, developmental disabilities & behavior disorders, age 3-22. Curriculum covers communication, academics, social & life-skills, employment.
http://www.necc.org
Circle # 76
See our ad on page C2

New Hampshire

Camp Allen, Inc.
56 Camp Allen Road
Bedford, NH 03110
(603) 622-8471
Fax: (603) 626-4295
Enjoy the summer at this 67 year-old camp with 3:1 camper:staff ratio, RN on site, and 6 or 12 day sess. Fish, swim, hike, arts, nature, phys. Rec, and tent camping.
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Crotched Mountain Rehabilitation Center
1 Verney Dr
Greenfield, NH 03047
(603) 547-3311
Fax: (603) 547-3232
Fully accredited by the NEASC and CARF, the Crotched Mountain Rehabilitation Center offers the very best of residential and day programs for children with complex special needs. Visit our Internet site at: http://www.cmf.org
Circle # 36
See our ad on page 125

Lakeview Neuro-Rehabilitation Center
101 Highwater Rd
Effingham Falls, NH 03814
(800) 473-4221
Fax: (603) 539-8888
www.lakeviewsystem.com
Circle # 64
See our ad on page 101

The Lukas Community
P.O. Box 137
Temple, NH 03084
(603) 878-4796
www.mv.com/org/luka
Circle # 68
See our ad on page 120

New Jersey

Bancroft NeuroHealth
Hopkins Lane, P.O. Box 20
Haddonfield, NJ 08033-0018
(800) 774-5516
www.bnh.org
Programs in NJ, DE, LA & ME. Serving children and adults with Autism, developmental disabilities and brain injuries. Offering a full range of education, vocational, therapeutic, rehabilitation and residential programs, plus behavior intervention, day treatment and diagnostic outpatient services.
Circle # 21
See our ad on page 79

1050

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LISTING OF SCHOOLS, CAMPS, & RESIDENCES

Hope With Heart
P.O. Box 618
Hewitt, NJ 07421
(973) 728-3854 Fax: (908) 497-1234
e-mail: bhurley@scny.org
A residential camp program for children with congenital heart disease. There are no fees to any parent. Medical Staff on-site.

Matheny School and Hospital
P. O. Box 339 Main Street
Peapack, NJ 07977
(908) 234-0011
Fax: (908) 234-2137
www.matheny.org
e-mail: info@matheny.org
Circle # 71
See our ad on page 92

New York

Karafin School
40 Radio Circle
Mt. Kisco, NY 10549
(914) 666-9211
Fax: (914) 666-9868

Pathfinder Villages for Down Syndrome
3 Chenango Road
Edmeston, NY 13335
(607) 965-8377
info@pathfindervillage.org

The Center for Discovery
P.O. Box 840
Harris, NY 12742-0840
(914) 794-1400 Ext. 1444
Fax: (914) 794-1615
e-mail: admiss@sdtc.org
Provides innovative and comprehensive services to children who have multiple disabilities and medical frailties. State-of-the-art, accessible, 50 acre campus. Come see us in action. We're like nothing you've ever seen.

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Anne Carlsen Center for Children
301 7th Avenue NW
Jamestown, ND 58401
(800) 568-5175
Fax: (800) 568-5175
www.annecenter.org

Ohio

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15000 Cheerful Lane
Strongsville, OH 44136
(440) 238-6200
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Fax: (503) 897-4116
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www.cotting.org

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Contact: Bruria K. Falik, Ph.D.
Camp Huntington
P.O Box 368
Woodstock, NY 12498
(914) 679-4903 Winter
e-mail: camphtgtn@aol.com

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- Community based group homes.

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Presbyterian Special Services
3395 Grand Avenue, P.O. Box 220036
Glenwood, FL 32722
(904) 734-2874/(800) 358-0450

The Duvall Home

Circle #42

LISTING OF SCHOOLS, CAMPS, & RESIDENCES

continued from page 121

Pennsylvania

Camp Joy
3325 Swamp Creek Rd
Schwenksville, PA 19473
(610) 754-6878
Fax: (610) 754-7880
www.campjoy.com
For kids and adults w/MR/DD. Our 26th year. Outstanding care & fun. Mobility acc. Year round programs.

Camp Lee Mar
805 Redgate Road
Dresher, PA 19025
(215) 658-1708
Fax: (215) 658-1710
www.leemar.com
e-mail:gtour400@aol.com

Camphill Special School
1784 Fairview Road
Glenmoore, PA 19343
(610) 469-9236
Fax: (610) 469-9758
www.beaverrun.org
Circle # 27
See our ad on page 118

Devereux
444 Devereux Drive
P.O. Box 638
Villanova, PA 19085
Toll Free (800) 935-6789
(610) 542-3030
Fax: (610)542-3141
Devereux-A nationwide network of residential and day treatment programs for children and adults who have a wide range of emotional and or developmental disabilities.
Circle # 39
See our ad on page 91

Dr. Gertrude A. Barber Center
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Erie, PA 16507
(814) 453-7661
Fax: (814) 454-2771
e-mail: gabemain@drbarber-center.org
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Fax: (610) 891-7600
www.elwyn.org
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HMS School for Children with Cerebral Palsy
4400 Baltimore Avenue
Philadelphia, PA 19104
(215) 222-2566
Fax: (215) 222-1889
Circle # 57
See our ad on page 112

Martha Lloyd Community Services
190 W. Main Street
Troy, PA 16947
(570) 297-2185
www.marthalloyd.org
Circle # 70
See our ad on page 76

Melmark
2600 Wayland Road
Berwyn, PA 19312
(888) MELMARK
Fax: (610) 353-4956
www.melmark.org
Approved private school, adult day programs, on/off campus residential alternatives for people with disabilities; 24 hour nursing care, OT/PT, speech, aquatics, horsemanship, recreation, multi-sensory programs. Call for more information.
Circle # 72
See our ad on page 11

1061

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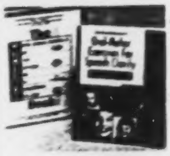
**THERAPISTS, CLIENTS
AND PARENTS**



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Housatonic, MA 01236
(413) 528-2523, Ext. 14
berkshiremeadows.org**

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Extension: 375

e-mail: Css372@aol.com

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410.634.2112

Circle #24

LISTING OF SCHOOLS, CAMPS, & RESIDENCES

Continued from page 123

South Dakota

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2501 W. 26th Street
Sioux Falls, SD 57105-2498
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http://www.cchs.org
Circle # 28
See our ad on page 118

Texas

Brown Schools Rehabilitation Center
1106 West Dittmar Road
Austin, TX 78745
(800) 252-5151 or (512) 444-4835
Fax: (512) 462-6636
www.brownschools.com/rehabcenter

Marbridge Foundation
Box 2250
Manchaca, TX 78652
(512) 282-1144
Fax: (512) 282-3723
www.marbridge.com
Our beautiful 300 acre ranch just outside Austin is home for adults over 18 years of age with mental challenges. We provide guidance, education, and a safe, loving environment. Residents enjoy the satisfaction of on- or off-campus employment and social interaction.
Circle # 69
See our ad on page 58

Vermont

Austine School for the Deaf and Hard of Hearing
60 Austine Drive
Brattleboro, VT 05301
(802) 258-9500
Fax: (802) 254-3921
http://www.state.vt.us/schools/aus/

Virginia

Cumberland, A Brown Schools Hospital for Children and Adolescents
9407 Cumberland Road
New Kent, VA 23124
(800) 368-3472 *804) 966-5639
www.brownschools.com/cumberland
Cumberland Hospital provides comprehensive medical, psychiatric, behavioral, and educational services to youngsters ages 2-22

Washington, DC

NAPSEC
1522 K St NW/Ste 1032
Washington, DC 20005
(202) 408-3338 Fax: (202) 408-3340
www.napsec.com
See our ad on page 119

Wisconsin

Bethesda Lutheran Homes & Services, Inc.
700 Hoffmann Dr
Watertown, WI 53094
(800) 369-4636
Fax: (920) 262-6513
http://www.blhs.org

Chileda Institute
1020 Mississippi Street
LaCrosse, WI 54601
(608) 782-6480
Fax: (608) 782-6481
www.chileda.org
Circle # 31
See our ad on page 120

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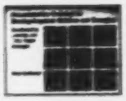

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This book peers under the umbrella of autism and looks at AS, a relatively new less debilitating autism-related diagnosis. Although first discovered in 1944, not much information has become available until the early 1990s with the establishment of a diagnostic criteria set forth by Gillberg and Gillberg. Here is shown that AS individuals are a bright thread in the tapestry of life and our civilization would be extremely dull and sterile if we did not have and treasure individuals with the condition.
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TONY ATWOOD
This book provides a description and analysis of the unusual characteristics, and practical strategies to reduce those that are most conspicuous or debilitating. There are numerous quotations form people with Asperger's Syndrome, as their insight and descriptions are more clearer and more poignant that the text in scientific journals. This is in layman terms with very little scientific terminology to impress or confuse the reader. Topics covered are: Diagnosis; Social Behavior; Language; Motor Clumsiness, Sensory Sensitivity and much more.
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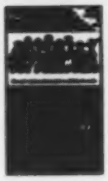

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[illegible] $25.00

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[illegible] $14.00

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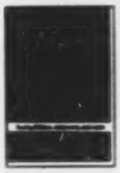

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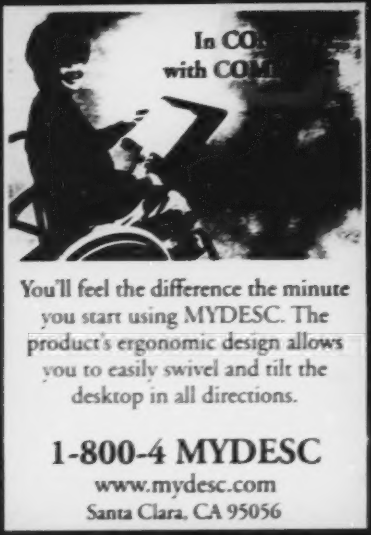
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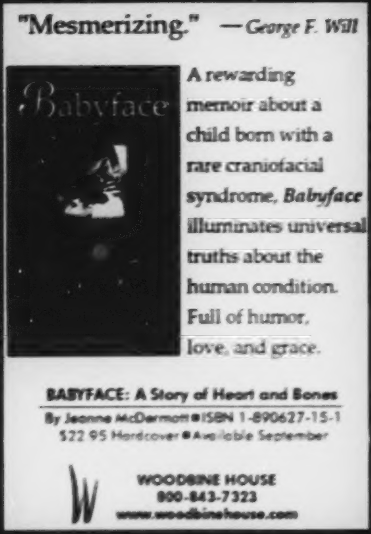
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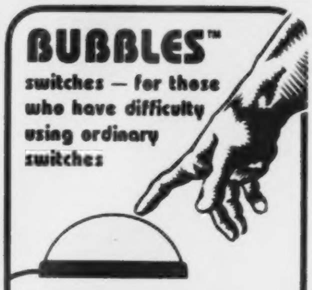

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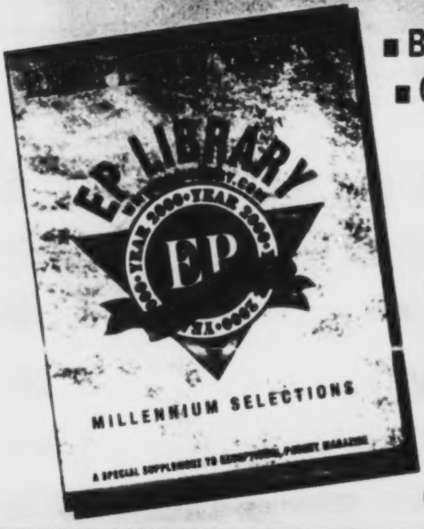

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The California Chariot Co., 1817 Aston Ave., Ste. 103, Carlsbad, CA 92008; Phone: (800) 781-8110; Web site: http://www.californiachariot.com; E-mail: sales@californiachariot.com

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A phonics-based reading program for children with learning disabilities, this educational software is a self-paced program with 47 interactive lessons and practice activities. The lessons utilize one-on-one instruction through video and audio clips that respond with appropriate feedback based on the student's performance. The lessons include strategies for encoding and decoding simple and multi-syllable words for boosting spelling and comprehension skills.

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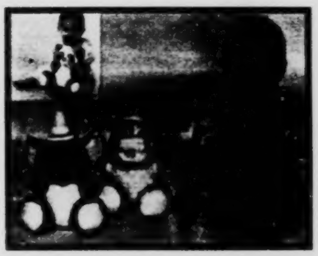
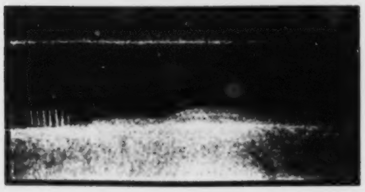


These bottle and cup holders are for infants and children with physical or neurological disabilities. The pillow-like pals can aid a child's ability to grasp their own bottle or cup and are cute and fun pals as well. They are made of washable nylon and terrycloth and can hold an 8oz. bottle or sippy cup. A drip cloth on the back makes wiping a baby's mouth easy.

Baby's Choice Corp., PO Box 2349, Monroe, MI 48161; Fax: (734) 384-0971; Web site: http://www.bottlepals.com; E-mail: sales@bottlepals.com



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The ABLEDATA database of assistive technology and rehabilitation equipment contains information on more than 25,000 products for persons of all ages who have a physical, cognitive, or sensory disability. Products are chosen for this page by the ABLEDATA staff based on their specific applicability to or design for children who have disabilities. ABLEDATA, operated by Macro International Inc., is funded by the National Institute on Disability and Rehabilitation Research under contract number HN-96015001.

For more information on these and other assistive devices, or to submit product information for the database (and possible inclusion on this page), contact: **ABLEDATA, 8630 Fenton St., Ste. 930, Silver Springs, MD 20910; (800) 227-0216 or (301) 608-8998 (voice); (301) 608-8912 (TTY); (301) 608-8958 (fax); Web site: http://www.abledata.com.**

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Alex Is Pretty Neat!

by Anna Pettus

I have a brother named Alex. He has Down syndrome. Down syndrome is when someone looks a little different and is a little late in learning things. I can think of a lot of words to describe Alex: different, loving, and special! I am going to tell you more about Alex.

Alex is 7-years-old, even though he looks like he is younger. He was born on December 29, 1993, which is four days after Christmas. Alex is in first grade in my school. A lot of kids in my class think Alex is pretty neat. Alex knows his A,B,C's and how to count to twenty. He loves to swim, ice skate, and play baseball, too. Our yellow Labrador, Jake, is a great buddy to Alex. They are like playmates.

This summer Alex and I went to a water park with some friends. We went down the water slides and rode the go-carts. We even played miniature golf. We had a ball! We also went bowling as a family. Daddy started to teach Alex, but then he got tired. Then I tried to teach him, and he learned how to hold the ball.

Alex and I are like normal brothers and sisters because we fight sometimes. We like doing things together, and we are good friends. I think I have a better relationship with Alex than if he were nondisabled. I like that he follows me around and copies everything I do.

No matter what my brother looks like, or if he has a disability, I will always love Alex just the same.

Anna is proud that her little brother Alex looks up to her.

Anna, 10, and Alex live in Dalton, Massachusetts. ■

Anna and Alex love being outdoors.

MOM'S TURN

According to her mother Lee Ann, Anna is very active. She loves to read and write and play soccer and softball. She also loves playing with her friends and, of course, being with Alex. "I think Anna and Alex have a wonderful relationship. Anna is very sweet and caring and likes to get him to tell her about his day at school." Lee Ann also adds that Alex is adjusting well at school. "We are very happy with the Dalton school system because they are strong supporters of full inclusion. It's been a wonderful experience for Alex and the other children to meet each other."

DAD'S TURN

Anna's father Mark says that when she speaks about Alex, Anna speaks from her spirit. "She has a somewhat maternal affection for her brother. Their relationship is genuine, not at all competitive. I think Alex's relationship with Anna is the most significant relationship in his life."

The Children's Page welcomes contributions from children who have disabilities, their siblings, and their friends. Be creative! Send your stories, photos and/or artwork to: Children's Page, Exceptional Parent, 555 Kinderkamack Road, Oradell, NJ 07649-1517. Be sure to include your name, address, and day-time telephone number! Now on the Web! We will now be including **Familiar Faces** and **Children's Page** on our Web site, www.eparent.com. Please send us your photographs with the understanding that doing so gives Exceptional Parent permission to put the photos on the Exceptional Parent Web site, exactly as they appear in the magazine and with the same text.

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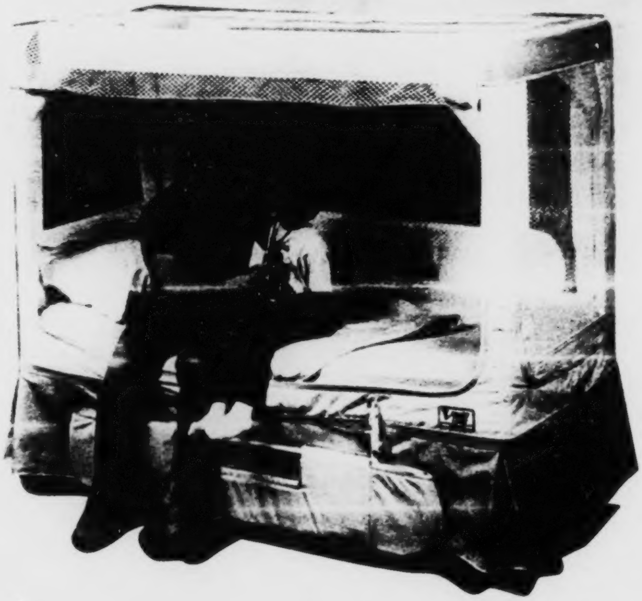

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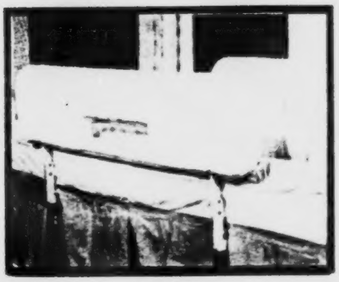

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CAN YOU FIND THE SYMPTOMS OF CARNITINE DEFICIENCY IN THIS PICTURE?

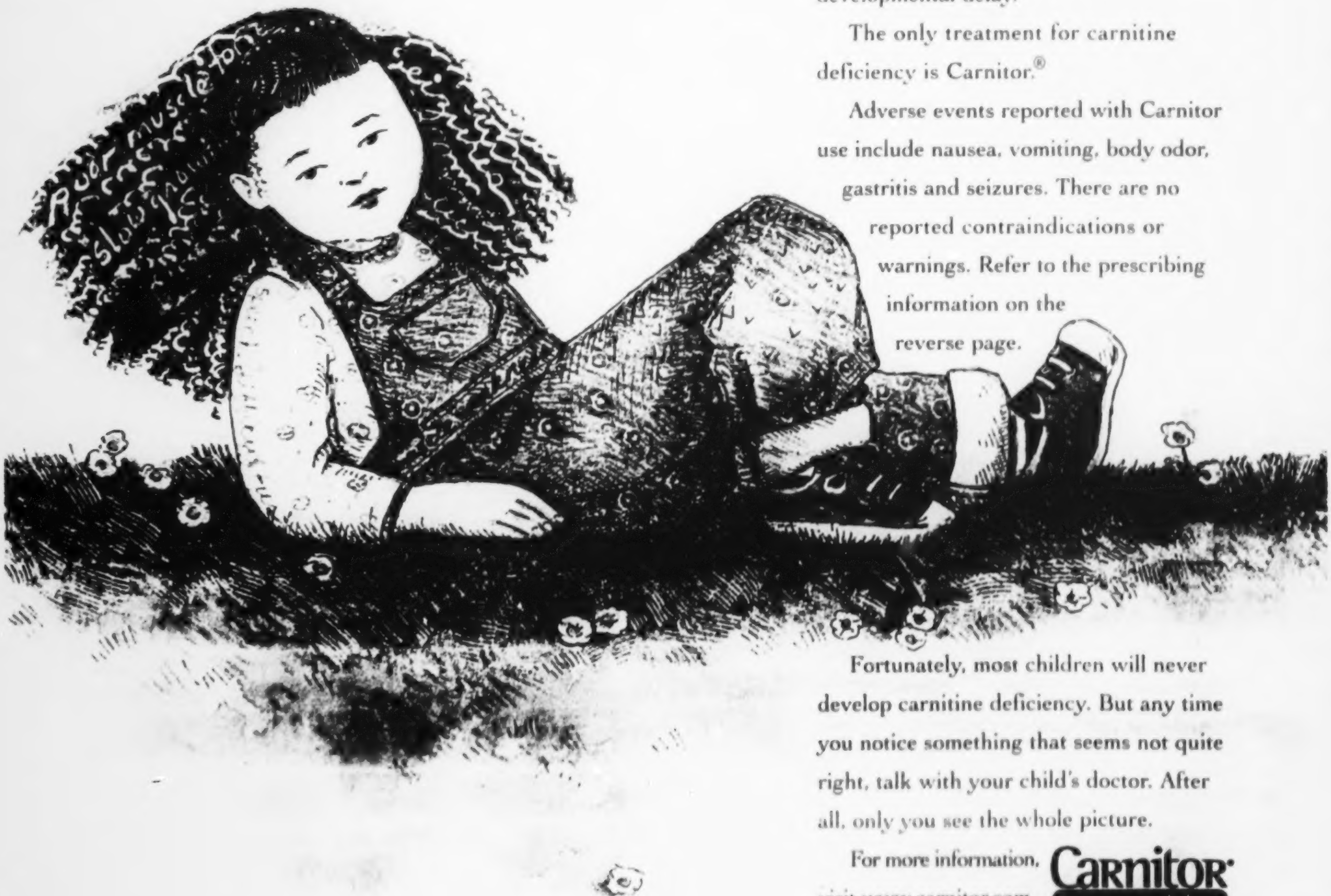
No one knows your child as well as you do. So no one's better at seeing the subtle things that affect your child's health. Things like carnitine deficiency.

Carnitine is a naturally occurring substance that's essential in the metabolic process. If the body is deficient in carnitine, the ability of the cells to produce energy and to remove toxic wastes is impaired. And while carnitine deficiency can be serious, its symptoms are hard to detect and are often overlooked.

Signs include muscle weakness, frequent infection, seizures, poor muscle tone, slow growth, speech difficulties, slow weight gain, lack of energy and developmental delay.

The only treatment for carnitine deficiency is Carnitor.®

Adverse events reported with Carnitor use include nausea, vomiting, body odor, gastritis and seizures. There are no reported contraindications or warnings. Refer to the prescribing information on the reverse page.



Fortunately, most children will never develop carnitine deficiency. But any time you notice something that seems not quite right, talk with your child's doctor. After all, only you see the whole picture.

For more information, visit www.carnitor.com. Or call 1-800-447-0169.

Carnitor®
levocarnitine
Tablets 330mg • Oral Solution 1g/10mL

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Circle #62

Carnitor®
levocarnitine

Tablets 330mg • Oral Solution 1g/10mL

CARNITOR® (levocarnitine) Tablets (330 mg)
CARNITOR® (levocarnitine) Oral Solution (1 g/10 mL multidose)
FOR ORAL USE ONLY. Not for parenteral use. Rx only.

BRIEF SUMMARY
The following is a brief summary. Please see package insert for full prescribing information.

CLINICAL PHARMACOLOGY
CARNITOR® (levocarnitine) is a naturally occurring substance required in mammalian energy metabolism. It has been shown to facilitate long-chain fatty acid entry into cellular mitochondria, therefore delivering substrate for oxidation and subsequent energy production. Fatty acids are utilized as an energy substrate in all tissues except the brain. In skeletal and cardiac muscle they serve as major fuel. Primary systemic carnitine deficiency is characterized by low plasma, RBC, and/or tissue levels. It has not been possible to determine which symptoms are due to carnitine deficiency and which are due to the underlying organic acidemia, as symptoms of both abnormalities may be expected to improve with carnitine. The literature reports that carnitine can promote the excretion of excess organic or fatty acids in patients with defects in fatty acid metabolism and/or specific organic acidopathies that bioaccumulate acyl CoA esters.

Secondary levocarnitine deficiency can be a consequence of inborn errors of metabolism. CARNITOR® may alleviate the metabolic abnormalities of patients with inborn errors that result in accumulation of toxic organic acids. Conditions for which this effect was demonstrated are: glutaric aciduria II, methyl malonic aciduria, propionic acidemia, and medium chain fatty acyl CoA dehydrogenase deficiency. Autointoxication occurs in these patients due to the accumulations of acyl CoA compounds that disrupt intermediary metabolism. The subsequent hydrolysis of the acyl CoA compound to its free acid results in acidosis that can be life threatening. Levocarnitine clears the acyl CoA compound by formation of acyl carnitine which is quickly excreted.

Levocarnitine deficiency is defined biochemically as abnormally low plasma levels of free carnitine, (less than 20 μmol/L at one week post term) and may be associated with low tissue and/or urine levels. Further, this condition may be associated with a ratio of plasma ester/free levocarnitine levels greater than 0.4 or abnormally elevated levels of esterified levocarnitine in the urine. In premature infants and newborns, secondary deficiency is defined as plasma free levocarnitine levels below age related normal levels.

BIOAVAILABILITY/PHARMACOKINETICS
In a relative bioavailability study in 15 healthy adult male volunteers CARNITOR® Tablets were found to be bio-equivalent to CARNITOR® Oral Solution. Following the administration of 1980 mg b.i.d., the maximum plasma concentration level (C_{max}) was 80 nmol/mL and the time to maximum concentration (T_{max}) occurred at 3.3 hours. There were no significant differences for AUC and urinary excretion observed between these two formulations.

In the same bioavailability study of 15 healthy adult males, CARNITOR® (levocarnitine) Injection administered as a slow 3 minute bolus intravenous injection at a dose of 20 mg/kg showed that free levocarnitine plasma profiles are best fit by a two compartment model. Approximately 76% of free levocarnitine is eliminated in the urine. Using plasma levels uncorrected for endogenous levocarnitine, the mean distribution half life was 0.585 hours and the mean apparent terminal elimination half life was 17.4 hours following a single intravenous dose.

The absolute bioavailability of L-carnitine from CARNITOR® Tablets and Oral Solution was determined compared to the bioavailability of L-carnitine from CARNITOR® Injection Intravenous in 15 healthy male volunteers. After correction for circulating endogenous levels of L-carnitine in the plasma, absolute bioavailability was 15.1% ± 5.3% for L-carnitine from CARNITOR® Tablets and 15.9% ± 4.9% from the Oral Solution.

Total body clearance of L-carnitine (Dose/AUC including endogenous baseline levels) was a mean of 4.00 L/hr. Endogenous baseline levels were not subtracted since total body clearance of L-carnitine does not distinguish between exogenous sources of L-carnitine and endogenously synthesized L-carnitine. Volume of distribution of the intravenously administered dose above baseline endogenous levels was calculated to be a mean of 29.0 L ± 7.1 L (approximately 0.39 L/kg) which is an underestimate of the true volume of distribution since plasma L-carnitine is known to equilibrate slowly with, for instance, muscle L-carnitine.

L-carnitine was not bound to plasma protein or albumin when tested at any concentration or with any species including the human.

INDICATIONS AND USAGE
CARNITOR® (levocarnitine) is indicated in the treatment of primary systemic carnitine deficiency. In the reported cases, the clinical presentation consisted of recurrent episodes of Reye-like encephalopathy, hypoketotic hypoglycemia, and/or cardiomyopathy. Associated symptoms included hypotonia, muscle weakness and failure to thrive. A diagnosis of primary carnitine deficiency requires that serum, red cell and/or tissue carnitine levels be low and that the patient does not have a primary defect in fatty acid or organic acid oxidation (see Clinical Pharmacology). In some patients, particularly those presenting with cardiomyopathy, carnitine supplementation rapidly alleviated signs and symptoms. Treatment should include, in addition to carnitine, supportive and other therapy as indicated by the condition of the patient.

CARNITOR® (levocarnitine) is also indicated for acute and chronic treatment of patients with an inborn error of metabolism that results in a secondary carnitine deficiency.

CONTRAINDICATIONS
None known.

WARNINGS
None.

PRECAUTIONS
General
CARNITOR® (levocarnitine) Oral Solution is for oral/internal use only.
Not for parenteral use.
Gastrointestinal reactions may result from too rapid consumption of carnitine. CARNITOR® (levocarnitine) Oral Solution may be consumed alone, or dissolved in drinks or other liquid foods to reduce taste fatigue. It should be consumed slowly and doses should be spaced evenly throughout the day to maximize tolerance.

Carcinogenesis, mutagenesis, impairment of fertility
Mutagenicity tests performed in *Salmonella typhimurium*, *Saccharomyces cerevisiae*, and *Schizosaccharomyces pombe* indicate that CARNITOR® (levocarnitine) is not mutagenic. Long-term animal studies have not been conducted to evaluate the carcinogenicity of the compound.

PREGNANCY
Pregnancy Category B.
Reproductive studies have been performed in rats and rabbits at doses up to 3.8 times the human dose on the basis of surface area and have revealed no evidence of impaired fertility or harm to the fetus due to CARNITOR®. There are, however, no adequate and well controlled studies in pregnant women. Because animal reproduction studies are not always predictive of human response, this drug should be used during pregnancy only if clearly needed.

NURSING MOTHERS
It is not known whether this drug is excreted in human milk. Because many drugs are excreted in human milk, a decision should be made whether to discontinue nursing or to discontinue the drug, taking into account the importance of the drug to the mother.

PEDIATRIC USE
See Dosage and Administration.

ADVERSE REACTIONS
Various mild gastrointestinal complaints have been reported during the long-term administration of oral L- or D,L-carnitine; these include transient nausea and vomiting, abdominal cramps, and diarrhea. Mild myasthenia has been described only in uremic patients receiving D,L-carnitine. Gastrointestinal adverse reactions with CARNITOR® (levocarnitine) Oral Solution dissolved in liquids might be avoided by a slow consumption of the solution or by a greater dilution. Decreasing the dosage often diminishes or eliminates drug-related patient body odor or gastrointestinal symptoms when present. Tolerance should be monitored very closely during the first week of administration, and after any dosage increases.

Seizures have been reported to occur in patients with or without pre-existing seizure activity receiving either oral or intravenous levocarnitine. In patients with pre-existing seizure activity, an increase in seizure frequency and/or severity has been reported.

OVERDOSAGE
There have been no reports of toxicity from carnitine overdosage. The oral LD_{50} of levocarnitine in mice is 19.2 g/kg. Carnitine may cause diarrhea. Overdosage should be treated with supportive care.

DOSAGE AND ADMINISTRATION
CARNITOR® (levocarnitine) Tablets

Adults: The recommended oral dosage for adults is 990 mg two or three times a day using the 330 mg tablets, depending on clinical response.

Infants and children: The recommended oral dosage for infants and children is between 50 and 100 mg/kg/day in divided doses, with a maximum of 3 g/day. Dosage should begin at 50 mg/kg/day. The exact dosage will depend on clinical response.

Monitoring should include periodic blood chemistries, vital signs, plasma carnitine concentrations and overall clinical condition.

CARNITOR® (levocarnitine) Oral Solution.
For oral use only. **Not for parenteral use.**

Adults: The recommended dosage of levocarnitine is 1 to 3 g/day for a 50 kg subject, which is equivalent to 10 to 30 mL/day of CARNITOR® (levocarnitine) Oral Solution. Higher doses should be administered only with caution and only where clinical and biochemical considerations make it seem likely that higher doses will be of benefit. Dosage should start at 1 g/day, (10 mL/day), and be increased slowly while assessing tolerance and therapeutic response. Monitoring should include periodic blood chemistries, vital signs, plasma carnitine concentrations, and overall clinical condition.

Infants and children: The recommended dosage of levocarnitine is 50 to 100 mg/kg/day which is equivalent to 0.5 mL/kg/day CARNITOR® (levocarnitine) Oral Solution. Higher doses should be administered only with caution and only where clinical and biochemical considerations make it seem likely that higher doses will be of benefit. Dosage should start at 50 mg/kg/day, and be increased slowly to a maximum of 3 g/day (30 mL/day) while assessing tolerance and therapeutic response. Monitoring should include periodic blood chemistries, vital signs, plasme carnitine concentrations, and overall clinical condition.

CARNITOR® (levocarnitine) Oral Solution may be consumed alone or dissolved in drink or other liquid food. Doses should be spaced evenly throughout the day (every three or four hours) preferably during or following meals and should be consumed slowly in order to maximize tolerance.

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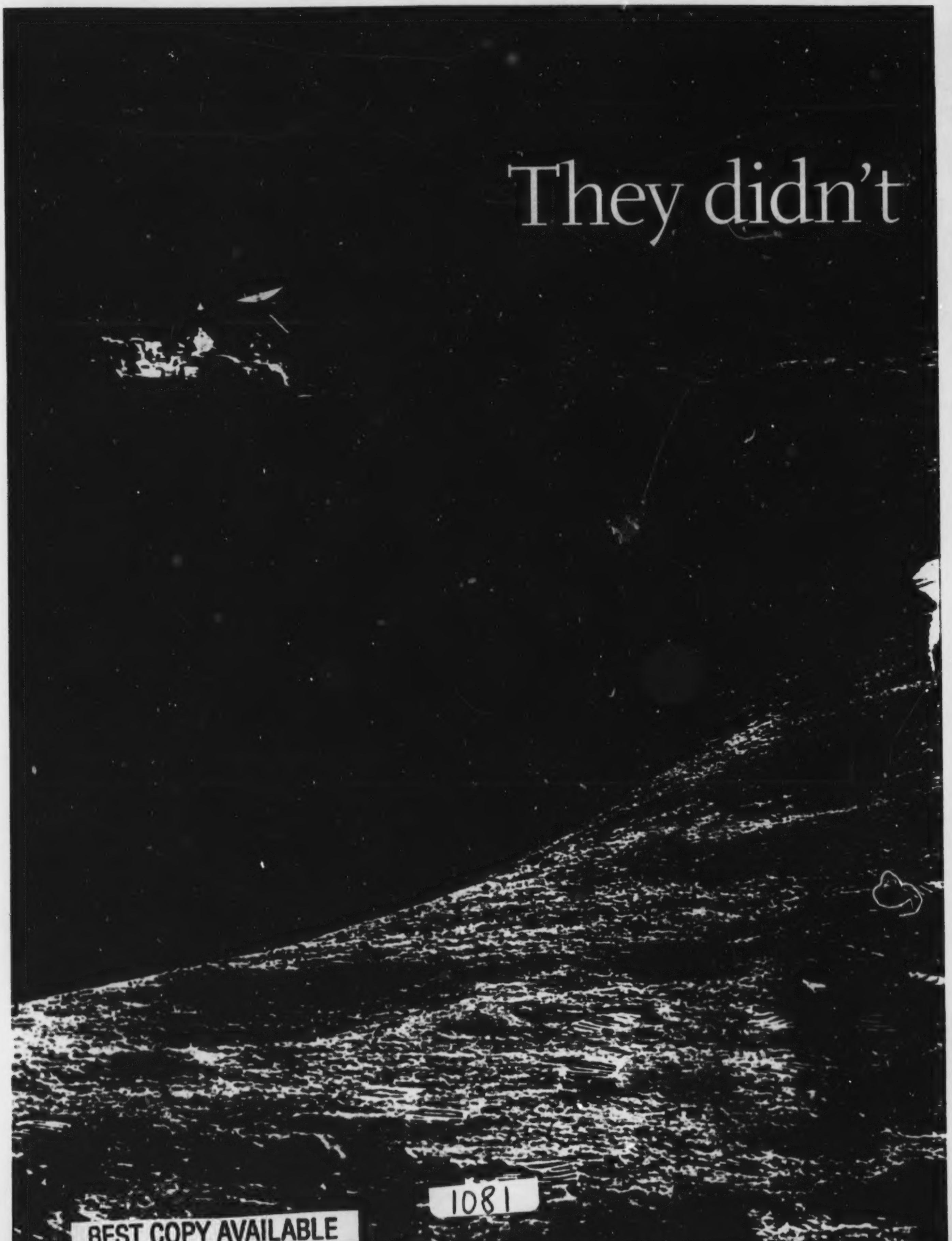

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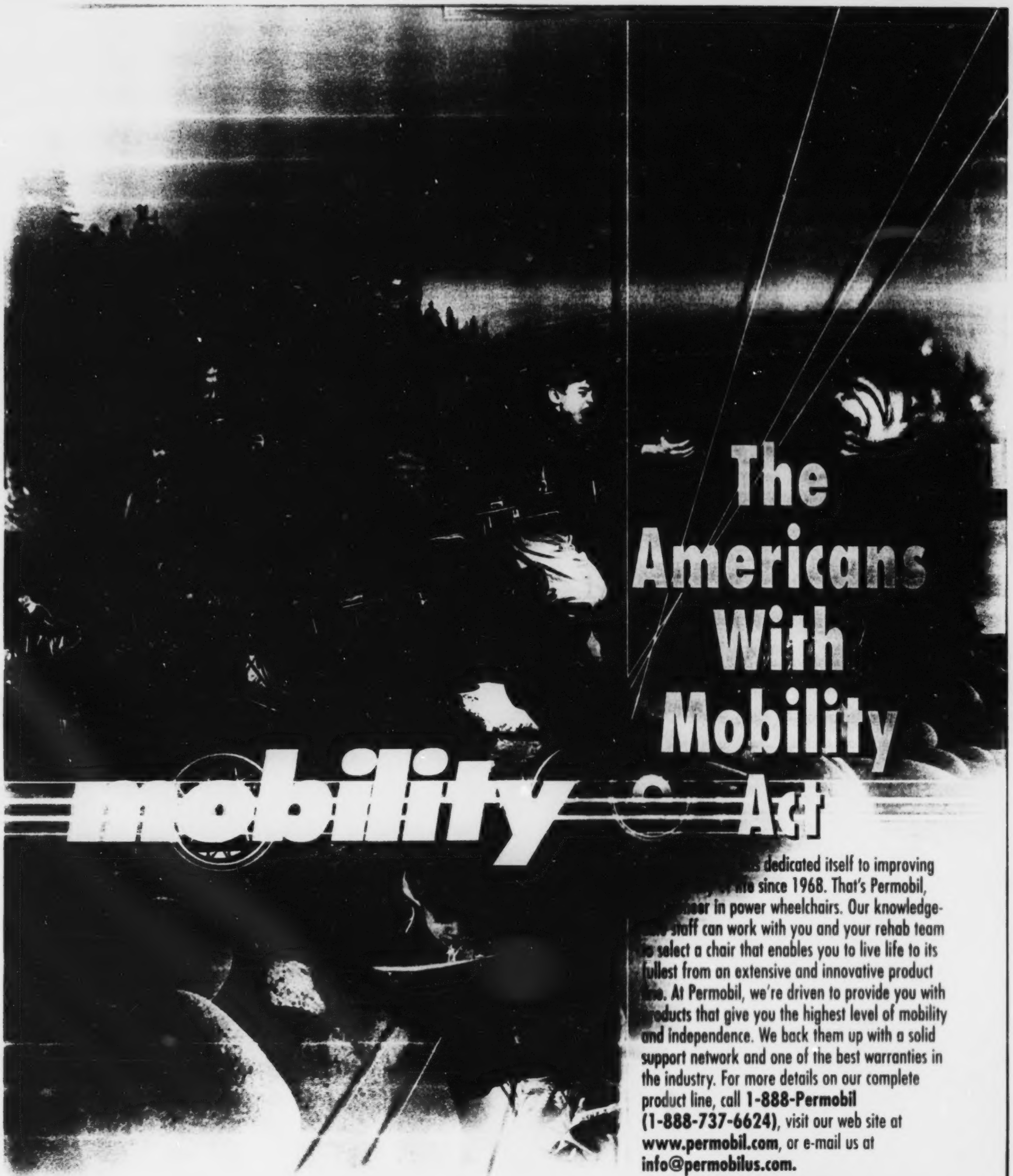

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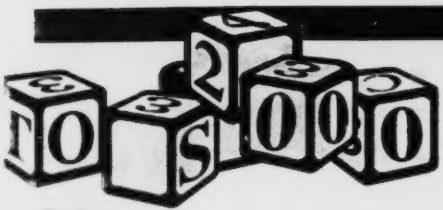

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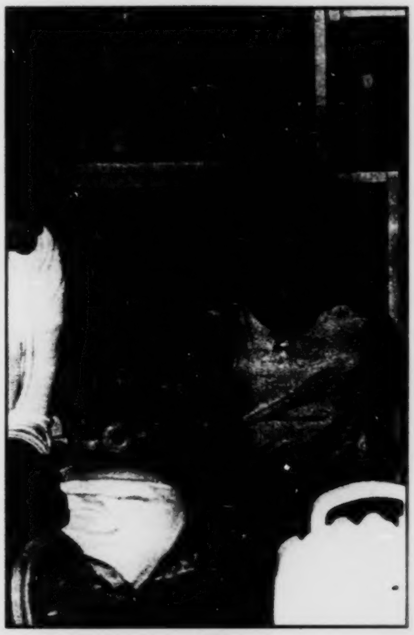

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COVER: Heather Senft (L), Trish Siegel, physical therapist, and Kymberli Bowser (R) are caught up in a game at the Center for Child Development, Ridgewood, NJ. Heather, 6, of Oakland, NJ, has spastic quadriplegic cerebral palsy. Kymberli, 7, of Trenton, NJ, has spastic diplegic cerebral palsy, ADD/ADHD, and mild PDD-NOS.

Special thanks to everyone at the Center for Child Development and to Flaghouse, Inc., for supplying toys. Photo by Michael Longobardi. Art direction by Ann Weber.

EP

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EDITORIAL MISSION

- TO REACH OUT TO MOTHERS AND FATHERS OF CHILDREN AND YOUNG ADULTS WHO HAVE DISABILITIES AND SPECIAL HEALTHCARE NEEDS.
- TO EMPOWER PARENTS AND PROFESSIONALS BY PROVIDING PRACTICAL INFORMATION AND EMOTIONAL SUPPORT.
- TO APPRECIATE THAT PARENTS ARE THE MOST IMPORTANT EXPERTS IN THE LIVES OF THEIR CHILDREN.
- TO ENERGIZE PARENTS AND PROFESSIONALS.
- TO SHARE IDEAS AND EXPERIENCES SO PARENTS, PROFESSIONALS, PEOPLE WHO HAVE DISABILITIES, AND OTHER ADVOCATES CAN LEARN FROM ONE ANOTHER AND BETTER COLLABORATE TO SERVE ALL CHILDREN AND FAMILIES.

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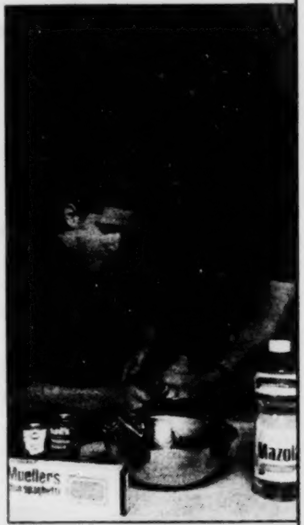

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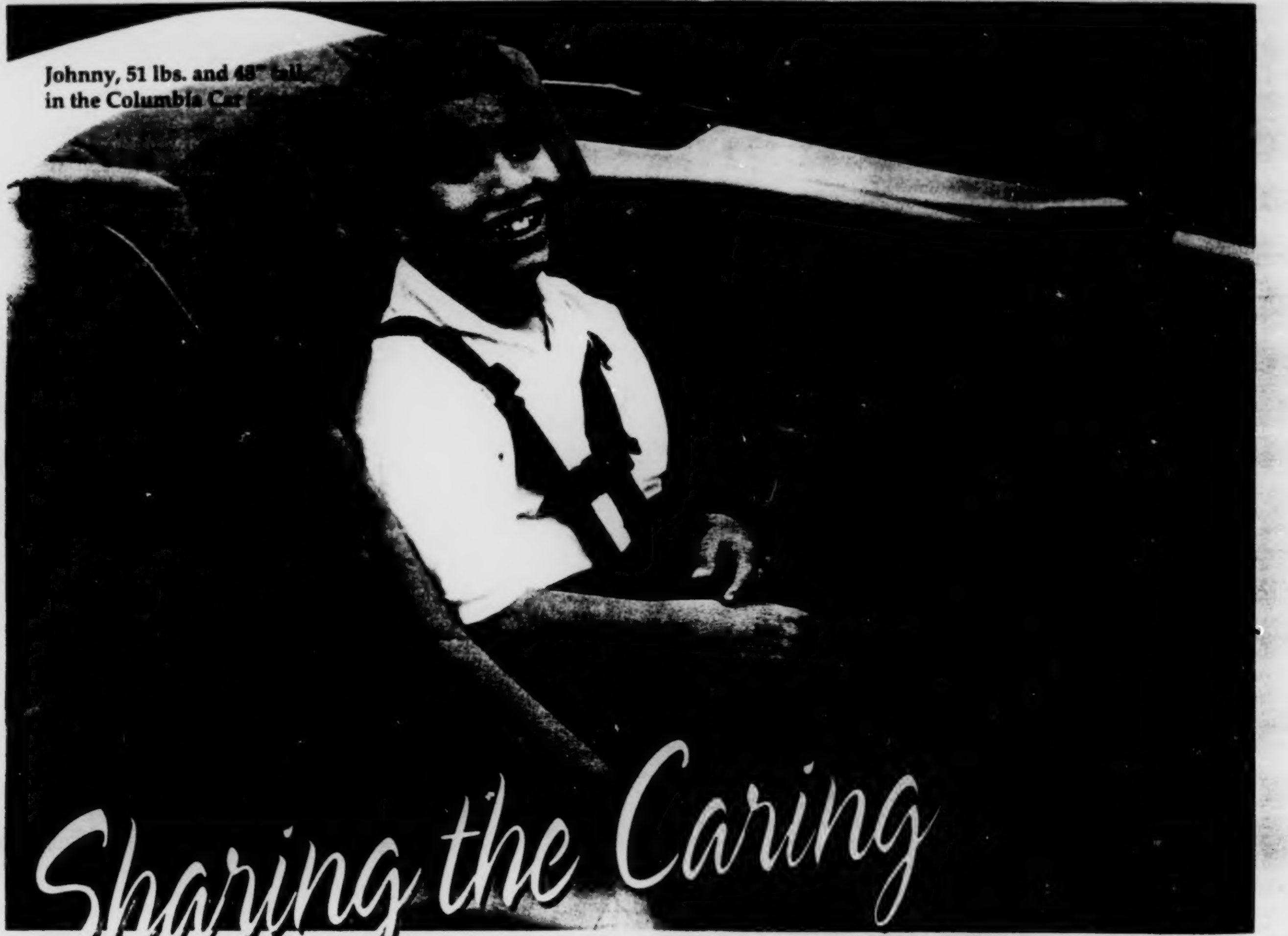

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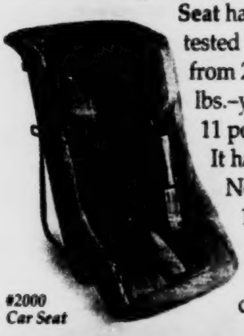

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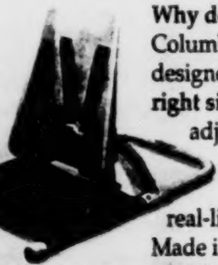

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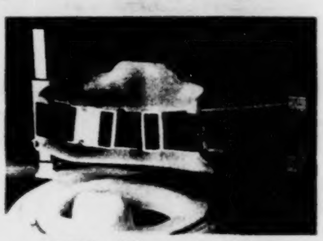

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Circle #26

A Time for Thanks and Reflection

Joseph M. Valenzano, Jr.
President, CEO & Publisher

It seems almost unbelievable, but Thanksgiving and the Winter Holidays are just around the corner once again. I always think of Thanksgiving as a time for reflection. Those of us at EP certainly have a lot to be thankful for, the most important of which is that after 30 years, we still have the good fortune to serve and be active participants in the community of people with disabilities. While the scope of what we do has expanded significantly over the years, we have kept in the forefront of our efforts the mission of our company: to provide practical advice and emotional support for families of children and adults with disabilities and special healthcare needs, and the professionals who are committed to their care and development. It is fitting then that as we enter our third decade, the EP family will host an extraordinary gathering on November 10-12, 2000 in Atlanta, Georgia, shortly before Thanksgiving: the World Congress & Exposition on Disabilities.

This event, the first of its kind ever in the world, brings together families, advocates, direct support professionals/caregivers, special education teachers, physicians, researchers, and the government. We have assembled internationally recognized leaders in their respective fields in an educational setting that spans the entire spectrum of disabilities including movement disorders, autism, mitochondrial and metabolic disorders, attention deficit/hyperactivity disorders (ADD/ADHD), learning disabilities, educational challenges, and parenting issues. Over 200 exhibits from quality product and service manufacturers will be on display, and events are planned for the entire family, including entertainment for children. The conference, a reflection of EP's mission, will focus on improving the quality of life for those with disabilities and special healthcare needs.

Health
INFORMATION

The EP family is also grateful for the acknowledgement we continue to receive for editorial excellence. I am happy and proud to share with you that EP was recently honored by the Health Information Resource Center with three National Health Information Awards in the Consumer Decision-Making Information class. The Awards recognize "the nation's best consumer health information programs and materials." The winning pieces—monographs produced by our Custom Communications Division—are based on articles which appeared as Special Reports in EP. They include: "Positive Perspectives for Cerebral Palsy;" "The Changing Nature of Epilepsy;" and "Vagus Nerve Stimulation: A new method in seizure management." Such recognition serves to motivate us to produce more educational and informative articles that can help families with special needs children as well as the professionals involved in their care.

With this and coming issues our staff and contributors are producing educational series' on Newborn Screening; ADD/ADHD; the Medical Home; and a follow up special report entitled "Contemporary Issues in Epilepsy." We are also in the midst of finalizing our series on incontinence. This month, EP Library will also be carrying two new books published by EP: "Patient Persistence" by Adele Gill, RN, and one on ADD/ADHD entitled, "No Apologies for Ritalin" by Vidya Bhushan Gupta, MD.

Beyond November lies the joyful winter season centered on gift-giving and children. In preparation for this EP has once again developed its Annual Toy Issue highlighting various articles on play, as well as a list of toys that are appropriate for specific disabilities. We have always been fortunate for the ever-growing pool of participants—parents and professionals—willing to share their time and expertise in creating the list. Indeed, EP's list of toys this year is longer than in previous years, and with a wider range of disabilities covered, including hearing impairments, visual impairments, physical impairments, autism, ADD/ADHD, and learning disabilities. As with last year, such coverage can also be accessed through the Web on http://www.eparent.com's Toy channel and its co-branded site, http://www.eToys.com.

Yes, we have a great deal to be thankful for. I hope to see you all in Atlanta this November at the World Congress & Exposition on Disabilities, where we can all share in the caring.

Sincerely,

Joseph M Valenzano Jr

Joseph M. Valenzano, Jr.
CEO, President & Publisher

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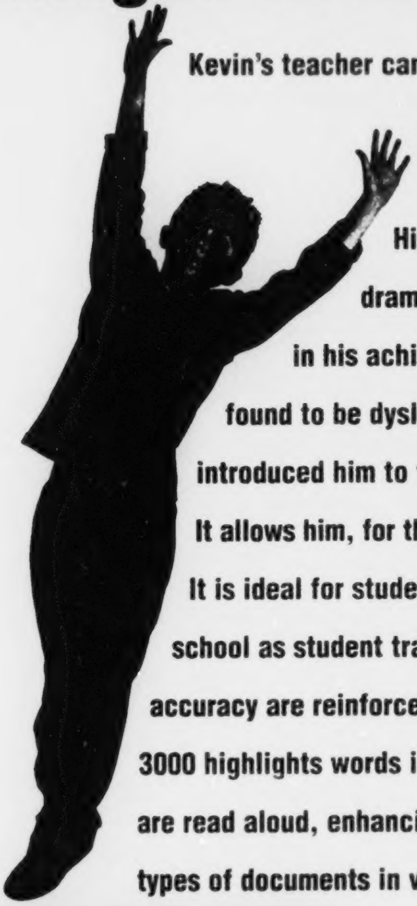
We Changed Kevin's Life



Kevin's teacher can't get over how much better Kevin is doing on his assignments. Kevin is having a great year in 4th grade. His reading and writing have improved dramatically and he's taking great pride in his achievements. Last year, Kevin was found to be dyslexic. That's when Kevin's teacher introduced him to the L&H™ Kurzweil 3000 software. It allows him, for the first time, to read independently. It is ideal for students in elementary school as student tracking and reading accuracy are reinforced. L&H™ Kurzweil 3000 highlights words in context as they are read aloud, enhancing the print in different types of documents in various ways to aid understanding. According to Kevin's teacher, "This software is wonderful! Kevin can now read independently. He now believes in himself and believes that he can achieve." Being able to read can change a life... just ask Kevin.

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Sincerely,

Sheldon O Zisook

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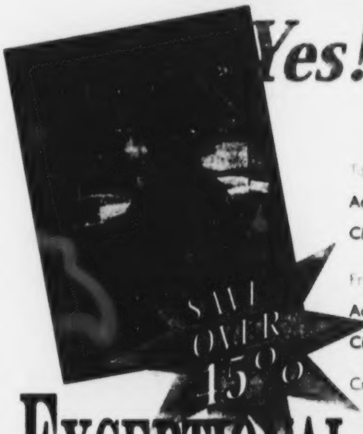

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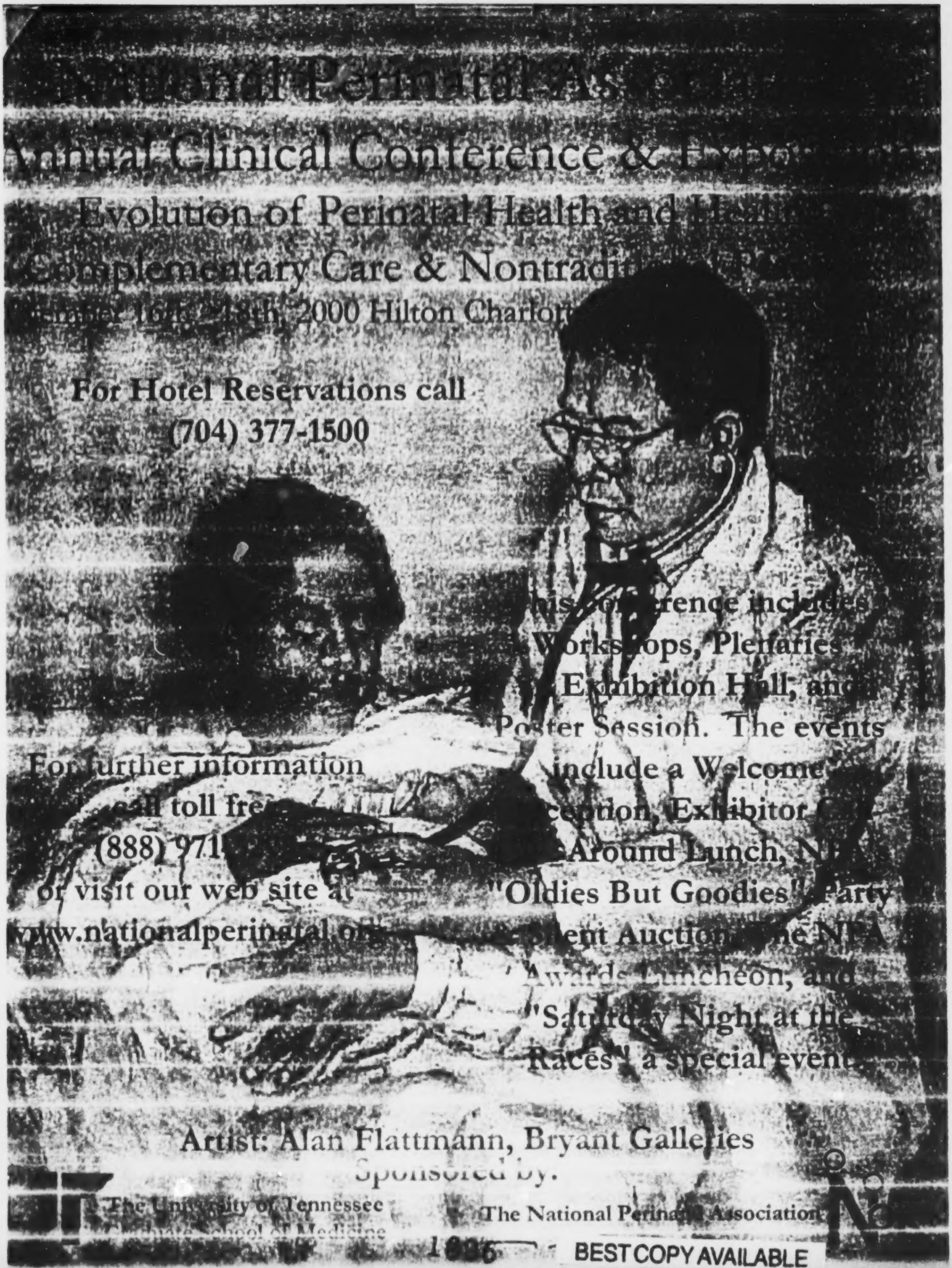

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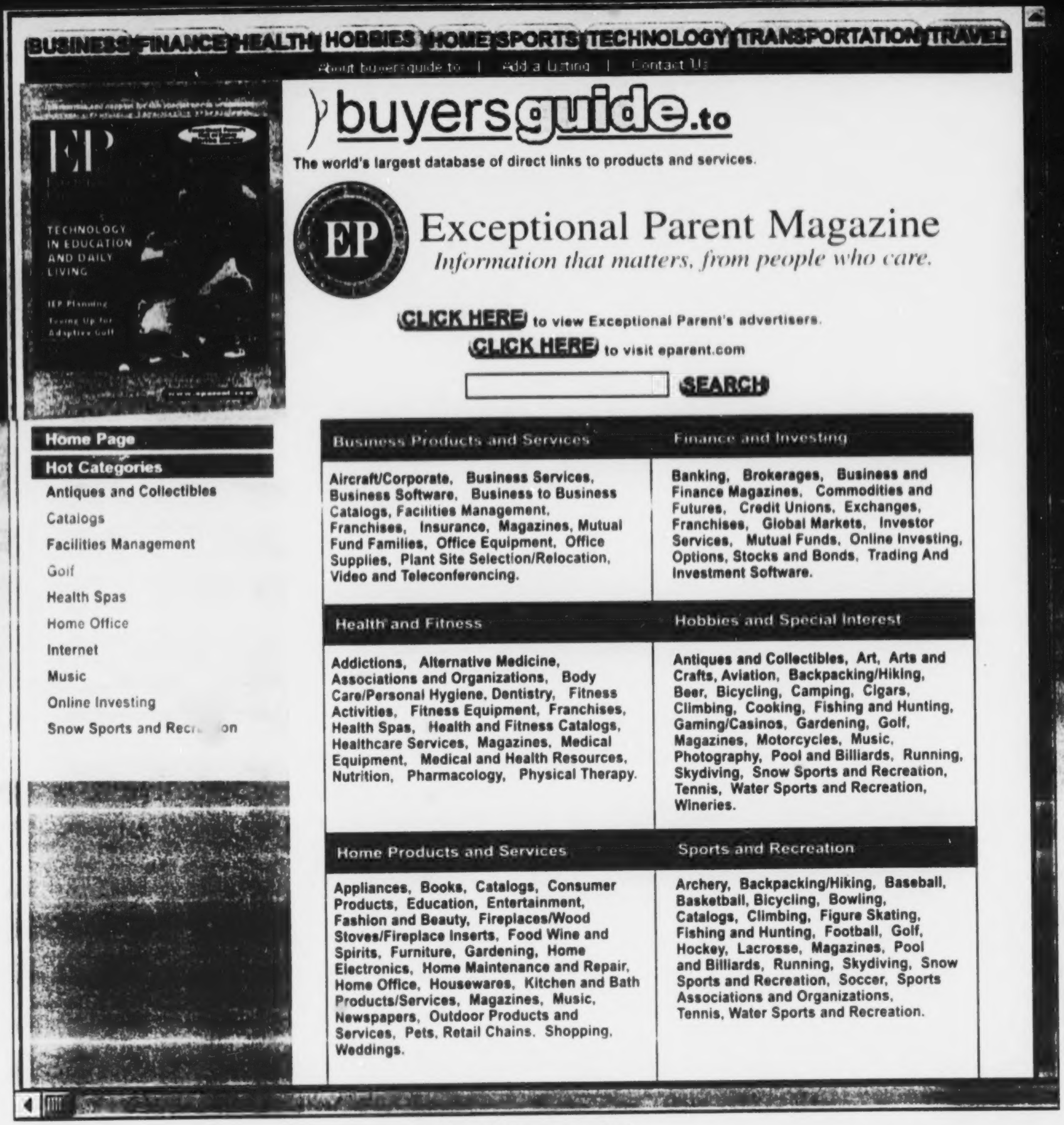
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Search & Respond

About Search & Respond

Search and Respond is an opportunity for our readers to exchange information about their practical experiences in meeting the everyday challenges of life with a child or adolescent who has a disability. In this column, "S" represents Search letters and "R" represents Respond letters received to a previously printed Search. "Instant S&R" is a new feature which represents e-correspondence we have downloaded from our Web site. All Responds are forwarded to the writers of the original Searches; some are published. Published letters may be edited for purposes of space and clarity. We also expect parents to consult appropriate professionals.

When sending correspondence, please indicate whether it is a Search or a Respond. For Responds, be sure to note in which issue the original Search letter appeared. Please remember to include a phone number on all correspondence, in the event that more information is required. Write to: Exceptional Parent, Attn: Search/Respond, 555 Kinderkamack Rd., Oradell, NJ 07649-1517; Fax to: (201) 634-6570; E-mail to epedit@aol.com; or visit Search and Respond on our Web Site: http://www.eparent.com.

For information about specific disabilities, contact: the National Organization for Rare Disorders (NORD), 100 Rt. 37, PO Box 8923, New Fairfield, CT 06812; (800) 999-6673; (203) 746-6518; Web site: http://www.rarediseases.org. Also, see the "National Resources for Specific Disabilities" directory in Exceptional Parent's 2000 Resource Guide (January 2000, starting on page 30).

Each month, Chris Feudtner, MD, PhD, reviews Search & Respond for accuracy and completeness. Dr. Feudtner is a pediatrician at the Pediatric Care Center of the University of Washington in Seattle, and is currently a Robert Wood Johnson Clinical Scholar. Look for Dr. Feudtner's comments on certain Search & Respond letters.

S

Power chair

A power wheelchair has been recommended for my 3-year-old son who has cerebral palsy. He has high muscle tone in his legs and arms, which affects his ability to walk and limits his fine motor skills and how well he maneuvers a joystick. His trunk tone is low, which affects his posture and speech quality. He is learning how to use a communication device that will need to be attached to his wheelchair. This is a big purchase for us and a long-term investment. My son will initially use the chair at preschool, and in more activities as he gets older. We do not have a van for transportation, so I am looking for a chair that will break down as simply as possible. The power chair we get for him at 3 years of age will also have to grow and work for him at 8 years, because of insurance requirements. Any thoughts or help would be appreciated.

RM, via the EP Web site

S

Looking for activities and information on hyperlexia

I have a 10-year-old daughter who was diagnosed with autism at age 6. Before that, she had constant ear infections with a sensitivity to dairy products. She was diagnosed with hearing impairment, speech impairment, mental retardation, a learning disability, and attention deficit disorder. She is in a special education program and uses an augmentative communication device. I have been trying to find activities to encourage her to use her device more and to improve her social skills. She enjoys music and dance, but I have not been able to find any activities that are appropriate for her.

I would also like to know more about hyperlexia. I have heard that it mimics the symptoms of autism.

KS, New York

Dr. Feudtner:
Hyperlexia describes the unusual ability of some children to recognize and "read" words, yet not understand the meaning of these words. Often, these children can "read" at levels far above what their cognitive development would predict, but without comprehension.

S

Child no longer drinking

My 5-year-old daughter has septo-optic dysplasia, which has caused her to have vision impairment, hypothyroidism, diabetes insipidus, and a seizure disorder. She is also developmentally delayed. Recently, she has stopped taking liquids by mouth and has had to get a feeding tube to keep her hydrated. She has been to several therapists. They have done every test possible and all they can tell me is that she is a stubborn child. Is there a specific professional I should see who can help my child drink again?

HH, Kentucky

S

Ratings for cities?

My son has cerebral palsy and is in a wheelchair. We live in a very rural area and have always encountered difficulty in finding needed services, recreation, and school programs even though the federal law mandates much of what we need. I have been considering relocation to a more disability-friendly area with more options for my son when he is an adult. Many sources exist for "rating" places, but none focus on the issue of accessibility and quality of life for someone with a disability.

NL, New York

Respond

R

Answers to questions

Heather (September 2000) has a 3-year-old daughter with cerebral palsy. Her daughter will be attending preschool and Heather wanted some ideas on how to respond to the children's questions about her daughter's disability.

I have an 18-year-old daughter with hemiplegia. When she was a child, I kept my answers to other children very simple. When someone asked about her AFO (ankle-foot orthotics), I told them it helps her walk better. To a question about why she walks differently, I would answer that her muscles do not work very well yet. If you answer simple questions willingly, a child will ask more when he or she wants more information. Preschoolers are just looking for simple answers to the basic "why" questions. They are not trying to evaluate her personality or weigh her worth.

Julianne, via the EP Web site

continued on page 20

Search & Respond

continued from page 19

R Exercises for a child with CP

ND (July 2000) has a 13-year-old daughter with spastic quadriplegic cerebral palsy and wanted to know if there are any easy exercises she could do at home to help relieve her daughter's spasticity.

Check with a physical therapist regarding suggestions for adaptive equipment that could be used to help your child. Often, a stander is used to encourage weight bearing and to increase muscle strength, and there are many activities a therapist could instruct you in that can be done at home in a fun, playful manner.

KB, via the EP Web site

R Does not empty bladder

LM (September 2000) has an 8-year-old son with Down syndrome who withholds his urine from early morning until late at night. He seems ready and willing to use the toilet, but appears to have an inhibition about "going."

If you have not taken your child to a pediatric urologist for a full exam, you really should consider it. It is unusual for anyone, especially a child, to hold their urine for more than eight hours. It may be that he is experiencing urinary retention. My son had urinary retention that went undiagnosed for years, slowly progressing until he came down with a severe urinary tract infection. Since that first infection three years ago, the infections have been hard to stop. I believe that if I had recognized his lack of regular urination as a problem sooner, he would not have the severe problems he has now. My son's doctor said that my son is incapable of urinating voluntarily. The main intervention for this is intermittent catheterization. I know that sounds just awful, but let me tell you, catheterizing your son is a thousand times better than watching him burn up with a fever because the urine sat in his bladder too long. You may want to consider taking him to a hospital that specializes in urinary problems for people with disabilities.

NB, via the EP Web site

EDITOR'S NOTE:

For more information on catheterization see "Incontinence: The Medical Story" (EP August 2000) and "Managing Incontinence: Helping Children Learn About and Overcome the Challenges" (EP September 2000).

You may also want to contact the following organizations:

The Simon Foundation for Continence—Phone: (800)-237-4666; Web site: http://www.simonfoundation.org. They provide a free information packet as well as other resources.

The National Association for Continence
Phone: (800) 252-3337; Web site: http://www.nafc.org.

Instant S&R

S Any good schools?

My 12-year-old daughter has ADD (attention-deficit disorder) and a learning disability.We are struggling with finding the right medication and dosage, frustration in schoolwork, and everything else that goes along with this. We will be moving from a small town with only public schools to Kansas City, Missouri, where the public schools recently lost their accreditation. I want to put my daughter in a private school, but all those I have come across do not offer special education services. How does a parent find a listing of schools and services available? Am I stuck with the public school system in this city?

Susan, via the EP Web site

R Do all you can to live outside this "crumbling" school district! Most private schools for special education students are for very specific needs, but by all means, seek them out and try to find one that is appropriate for your daughter. Contact CHADD (Children and Adults with Attention Deficit Disorder) and hook up with some other parents and get their opinion of the schools in your area. Also, take some time and do some research on the Web. Also, be sure to check schools' attitudes as well as services in this new city—it is just as important for your daughter's success.

Nancy, via the EP Web site

EDITOR' S NOTE:

CHADD can be reached by phone at (800) 233-4050. Their Web site is: http://www.chadd.org You may also want to contact the National ADD Association. The phone number is (800) 487-2282; their Web site is: http://www.add.org

S Menstruation

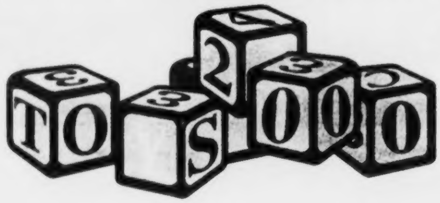
My daughter is 10-years-old and has developmental delays. She functions at about the level of a 2- or 3-year-old, is non-verbal but able to communicate her wants and needs by using pictures and pointing. I would like to know what to expect when she starts menstruating. I have tried researching this issue and found nothing on the subject. How do parents handle menstruation in their daughters with developmental delays?

AM, via the EP Web site

R My daughter's pediatrician brought this subject up recently. He stated that since my daughter's cognitive level is not high enough for her to be able to comprehend what will be happening to her body, that it would be better for her not to have her menstrual cycles. He recommended hormonal medication that would stop her periods. To be honest, I appreciate that, because she is not potty trained. I suggest you speak to your daughter's pediatrician and see if he or she has any recommendations in this area.

SB, via the EP Web site

EP'S TOYS 2000



Toys and games attract children on many levels; they are drawn to toys when they can merely see or grasp them. The pleasure children experience when they are engaged in playing helps them learn and explore the world around them. It contributes to physical, psychological, and social development. Children play by themselves and with members of their own families at first, and eventually with other children in their neighborhood and at school. But what happens when a child has limited vision and cannot see a toy? Or when a child has a physical impairment that hinders his or her ability to grasp and activate a toy? Or when a child cannot understand the rules of a game? Children who experience these difficulties are often excluded from play.

There are many toys that have been specifically created to enable children with disabilities to enjoy playing for fun as well as personal growth and development. Recently, however, more "mainstream" toy and game manufacturers are crafting their products with features like large buttons; bright colors; sturdy, easy-to-manipulate parts, and open-ended rules which have made them easily accessible and enjoyable for children of varying abilities.

With access to popular toys and games, children with disabilities can join in the fun together with their non-disabled peers. Parents of children with disabilities have learned that their children can play with the same popular toys and games their friends enjoy, perhaps with a little modification and by choosing them with careful attention to their child's abilities. Their knowledge of their child is the key in choosing toys and games that will be appealing and useable, as well as in adapting them and changing rules so that the child with disabilities is able to participate and have fun, just like any other child.

PHOTO COURTESY OF V-TECH INDUSTRIES, INC.

For this year's toy issue, the experts we invited to participate comprise both parents and professionals. The parents in this group each have a child (or children) with a disability in one or more of the categories and the pros have spent years working closely with children with special needs. The toys selected are those that were fun for the kids and beneficial too. The categories of disability we have this year are: hearing/speech impairment, vision impairment, physical impairment, attention deficit/hyperactivity disorder, autism, and learning disability. Many toys will have cross-over benefits and are suitable for all categories. The following pages will give you an idea of some choices for easy-to-find toys that may be just right for your child.

—The Editors

AUTISM/AUTISTIC-LIKE DISORDER

SHAPE-SORTER TOTE-ALONG BALL

—6 months to 3 years

FISHER-PRICE APPROX--$11.99

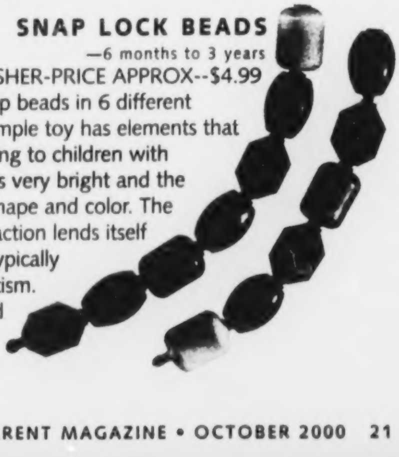
This toy is made up of six variously shaped/colored blocks that match shapes cut out on a portable plastic ball. The child fits each block into its matching shape cut out on the ball. Children with autism are typically fond of sorting by shape, color, etc. They are also visually acute and should enjoy recognizing which block fits into which shape.

8

SNAP LOCK BEADS

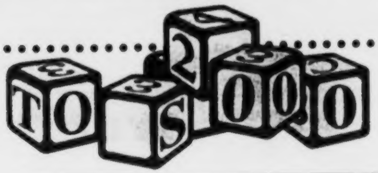
—6 months to 3 years

FISHER-PRICE APPROX--$4.99



This toy has 12 plastic snap beads in 6 different shapes and colors. This simple toy has elements that may be especially appealing to children with autism /PDD. Visually, it is very bright and the beads may be sorted by shape and color. The snapping and unsnapping action lends itself very well to repetition, also typically enjoyed by children with autism. Two boxes are recommended for added fun and sorting/snapping possibilities.

8



AUTISM/AUTISTIC-LIKE DISORDER

MY SIZE PUZZLE: BEAR IN THE BIG BLUE HOUSE

(not pictured)—4 years and up
MATTEL--$6.99

This is a 46- piece jigsaw puzzle of the popular Bear in the Big Blue House. When put together, the Bear and his kite are 3 feet long. Children with autism tend to be very visually acute. They can quickly identify which puzzle pieces fit into the appropriate places.

8

MAP OF THE USA

(not pictured)—4 years and up
LIVING & LEARNING--$14.99

This 61-piece puzzle is a good way for children to learn about the 50 states. Many of the puzzle pieces are cut in the actual shape of the state. Pieces are large, and have the states' capitals printed on them. When completed, the puzzle measures 2 feet by 3 feet.

8

BOGGLE JR AND BOGGLE

—6 to12 years, 12 to17 years
PARKER BROTHERS --APPROX. $17.99

Word finds and Word searches are especially appealing because the visual acuity of children with autism makes "word detection" a fun and typically successful activity. Boggle is equipped with 16 letter cubes and a frame to hold them. Each side of the cube has a letter. The goal is to find words that can be made by going up, down, sideways, and diagonally. Instead of playing for points, the object can be to count the number of words made. A timer is typically used but time periods can be extended or done away with according to a child's abilities and temperament.

7, 8

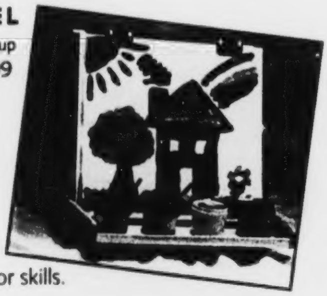
VISION IMPAIRMENT

SHAPES AND PUZZLES WITH HAPPY SOUNDS

—12 months and up
SASSY--$16.99

Three happy sounds reinforce learning by rewarding a child's success each time one of the shapes is correctly placed. A handle and cover make this toy great for travel. Encourages thinking and learning while developing fine motor skills. **13**

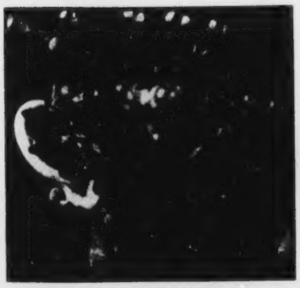
TABLETOP EASEL



—3 years and up
ALEX--$39.99

This all-in-one hardwood easel features a green chalkboard on one side and a dry erase board on the other. A convenient tray with built-in openings hold the 4 non-spill paint cups and 4 paint brushes. Promotes creative expression and fine motor skills.

13



KOOSH BUBBLES: BUBBA BILLIONS

—3 years and up
Oddzon--$9.99

Dip this colorful bubble machine into the solution tray and push the button to create billions of bubbles. Comes with Koosh Bubbles solution and tray. Promotes motor skills and creativity. Requires four AA batteries.

13

HAPPY SHAPE

—6 months and up
TOMY--$13.99

Babies will have fun learning shape recognition as they reach inside this playful shape sorter to choose a shape, or push shapes through openings on the other end. Chunky, three-dimensional shapes are easily recognizable by touch. Promotes fine motor coordination. **13**

LIGHT N' SOUND CLOWN

—3 to 18 months
CHICCO USA--$4.99

Baby's first electronic toy, this easy-to-grasp rattle features lots of flashing lights, colorful rattling balls and a musical melody activated simply by shaking it. Promotes awareness of sound and stimulates available vision.

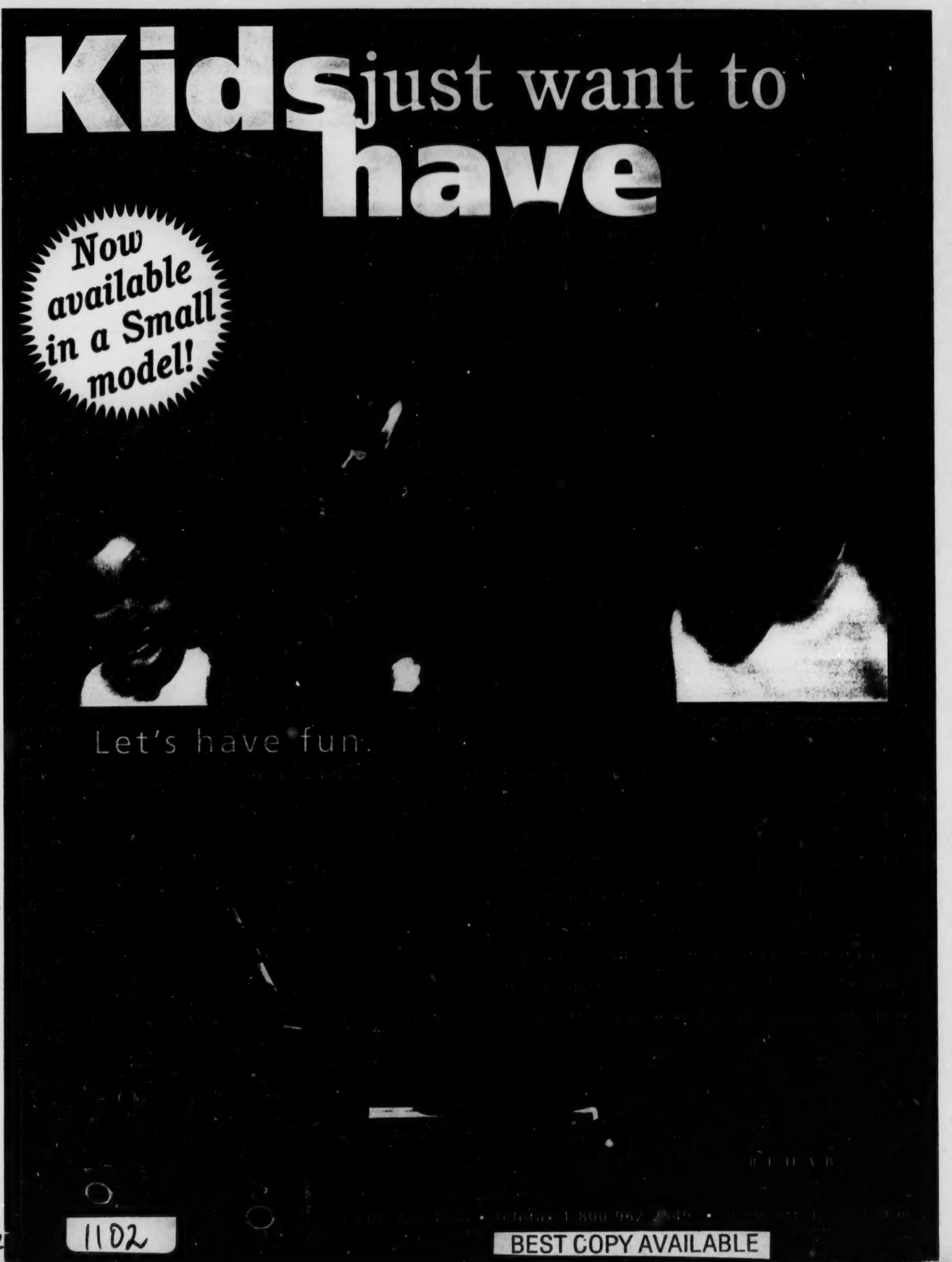
13

BABY MICKEY HUGLIGHT

(not pictured)—6 months to 2 years
FISHER-PRICE--$9.99

When Baby Mickey is hugged, his face lights up, acting as a night light. Mickey has brightly colored pajamas and is a comforting bedtime companion. Light helps stimulate a child's residual vision.

10



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VISION IMPAIRMENT

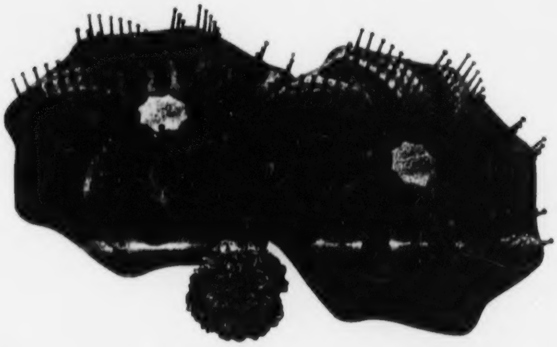
SPARKLING SYMPHONY MIRROR

—birth to 12 months

FISHER-PRICE--$11.99

This toy is star shaped with a large mirror at the center, surrounded by multi-colored points, with a spinable barrel at the bottom. The toy plays 2 classical tunes and 3 children's songs when the child spins the barrel. Once the wheel on the bottom of the toy is spun, the music starts and the multi-colored lights that encircle the mirror begin to blink, encouraging the child to reach out and use any residual vision he or she may have. The parent may explore positioning the child in different ways while he or she views and plays with the toy. The music has two settings: a long-play version for newborns and a shorter play version for the older child who can repeatedly spin the barrel.

2



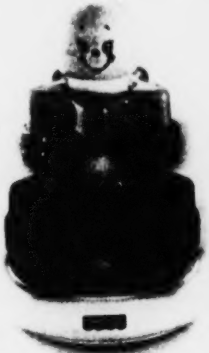
KOOSH CATCHERS

—7 years and up

ODDZON--$19.99

Koosh Catchers are plate-size paddles that are attached to the palm of the hand with a Velcro band. The face of the disc is bristled in a spiked pattern. The koosh ball is made of looped elastic strings that catch on the bristles of the paddles so it will not bounce off if caught. The ball will not roll away if dropped. The paddles and balls are bright contrasting colors. This game encourages activity, exploration of the environment, and sensory motor coordination. It is a game that can be played with a partner. It may be easier for a child with impaired vision to catch if a small bell is attached to the koosh ball.

2



SPARKLING SYMPHONY STACKER

—6 to 18 months

Fisher-Price--$11.99

This stacking toy has light and sound components. When the star-shaped rings are stacked they light up and sound effects play. The lights dance to this music. This toy encourages the development of motor coordination. In addition, cause and effect relationships are illustrated since the audio component plays only when the child pushes the crown or places a ring on the stacker. The lights may encourage any residual vision.

2

RAZOR SCOOTER

(not pictured, but you've seen them around)—5 years and up

RAZOR--$99.99

This wide-platform scooter with a non-slip surface has horizontal handle bars that control the front wheel (similar to a bicycle). The child can control this scooter with the precision of a bike yet have the security of being able to contact the ground with one foot to determine changes in the terrain. Using this toy requires balance, motor coordination, strength, orientation skills, and endurance. Supervision should be provided, appropriate to the age and skill level of the child. Constructing a course within a safe area can help the child feel more independent which becomes important as the child grows. The scooter also encourages physical exercise that is missing in many young people's lives, especially those with visual impairments.

2

RAZZLE DAZZLE JUMP ROPE AND HOOP

—6 years and up

MAUI TOYS--$9.99

Classic jump rope and hula-hoop made of clear plastic with colorful plastic decorations inside. The toys encourage motor skills, development of coordination, and body awareness. The toys can be used indoors while practicing and then moved outdoors for group play and competitions. They can be used while stationary so the child can concentrate fully on movement of the body parts, moving them faster and faster and not worrying about obstacles.

2

RAZZLE DAZZLE

PHYSICAL IMPAIRMENT

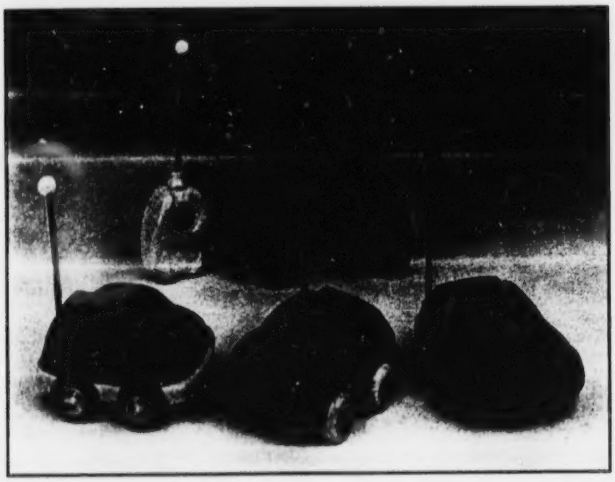
BALL ACTIVITY

—12 to 18 months

GYMNIC--$38.00

The Ball Activity is a clear ball with several colored balls inside, which move freely when the ball is rolled or bounced. Used to help improve gross motor skills, the ball can be used in group activities as well, which helps with social/emotional skills.

3



RC CAR

—3 to 5 years

Battat--$24.99

With a single push, this car zooms around and performs several stunts. There is only one button on the wireless remote needed to make it go. Your child will watch and wonder—where will the little car go next?

4

Hi Ho!
Cherry-O

Hi Ho! Cherry-O

HI-HO CHERRY-O

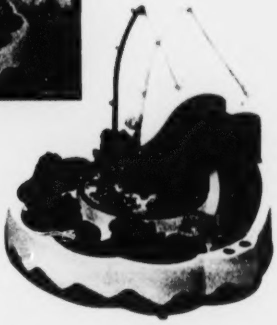
—3 to 6 years

PARKER BROTHERS--$9.99

This is a first counting game. Spin the spinner and pick the cherries from their trees. Pictures and numbers indicate how many cherries should be taken from the trees. This game is good for teaching counting and dexterity.

1

FISHIN' AROUND



FISHIN' AROUND GAME

—3 to 7 years

MILTON BRADLEY--$17.99

Eight swimming fish go around and around in this mechanized game. The object is to catch the moving fish with magnetized fishing poles. Music plays while game is running. Good for building motor planning skills.

1, 10

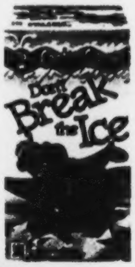
DON'T BREAK THE ICE

—3 to 6 years

MILTON BRADLEY--$8.99

Children can have fun knocking out blocks of "ice", while trying not to let the little man on the ice fall in. Players must think about what their next move will be. Uses fine motor skills.

1,10



Cootie Games
Don't Spill the Beans

DON'T SPILL THE BEANS

—3 to 6 years

MILTON BRADLEY--$8.99

The object of this game is to drop the beans into the pot one by one, while trying not to tip the pot over. The first person to get rid of their beans without spilling them wins. Works on pincer grasp.

10

1104

PHYSICAL IMPAIRMENT

COLORFORMS

—3 to 6 years

UNIVERSITY GAMES--APPROX $10.00

Colorforms are sticker-like pieces of flexible plastic that adhere to the special Colorforms Board as well as many other surfaces. Available in many different sets, with different characters, Colorforms are good for working on fine motor skills.

10

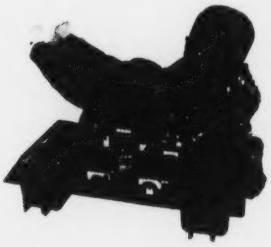
HOP! 45

—3 to 6 years

LEDRA PLASTIC--$19.99

A big, brightly colored hopping ball, with a handgrip for safety. Eighteen inches in diameter, the ball can be used indoors or outdoors and works to strengthen leg muscles, coordination, and balance.

10



LEGO BIRTHDAY TABLE

—5 to 12 years

LEGO--$19.99

This is a starter Lego set containing all that's needed to start building . It has a bright red playtable with handles for easy transport. The table can be used on laps or tabletops. Comes with 400 Lego bricks. Fitting pieces together is good practice for fine motor skills.

10

POUND-A-BALL

—18 months to 4 years

SMALL WORLD TOYS--$14.99

Learning cause and effect is fun with this toy. The brightly colored balls are hammered through the corresponding holes, roll down three ramps, spin a spinner, and roll out the bottom. Balls can also be pushed down with chins, noses, feet, etc. **10**

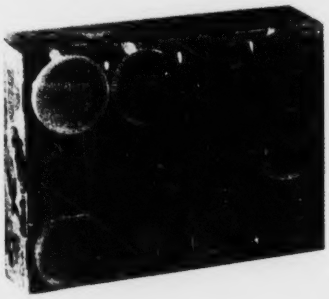
RUFF 'N TUMBLE BALL PIT

—2 to 5 years

HEDSTROM CORPORATION--$49.99

An inflatable fort that doubles as a ball pit, this toy is safe and fun. Comes with 100 multicolored balls and a vinyl patch kit if the walls need repairing. Toys can be hidden in the ball pit and children can hunt for them.

10



PLAY-DOH: CASE OF COLORS 10-PACK

—3 to 8 years

HASBRO--$7.99

A big box of modeling compound, featuring ten brightly-colored cans of Play-Doh. Molding and rolling Play-Doh works on creativity and fine motor skills.

10

TONKA MOTORIZED SEARCHLIGHT TRUCK

—3 years and older

Tonka
MOTORIZED

TONKA--$29.99

Good for all children with any disability, especially good for those with fine motor skill problems. Has large, easy to use switches to activate lights. Very well constructed of strong materials,which should be rugged and long lasting.

9

KICKBOARD

(not pictured)—2 years and older

SUN POINT CO., LTD--$3.99 (Kickboards are available from various manufacturers)

This is excellent for children and youth with any disability. Requires ability to hold onto a light-weight board. For use in swimming pools, excellent for both swimmers and non- swimmers. **9**

PHYSICAL IMPAIRMENT

GOLDENBOOK SEEK/SOUND CLASSROOM

(not pictured)—6 to12 years

GOLDEN BOOKS--$7.99

This item gives the child clues, sounds, and questions to find specific things in the picture (this one happens to be a classroom). Easy to access and uses a very light touch to play with. If you press an incorrect item, it will allow you time to select another.

6

BABY BEAR'S READ ALONG

(GOLDILOCKS AND THE 3 BEARS) (not pictured)—6 to 12 years

TORMONT EUROPE LTD.--$14.99

This toy comes with a plush bear and book. The numbers 1 through 6 are on his toes. When each number is pressed the bear/book story coincide. You can hear the story while seeing the printed words for word recognition. Easy to manipulate using a light touch.

6

HUNGRY, HUNGRY HIPPO

—6 to 12 years

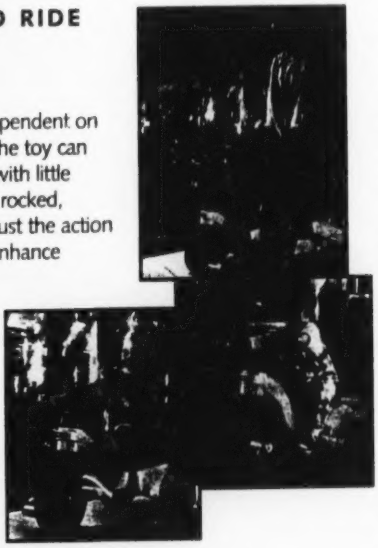
MILTON BRADLEY--$5.99

(There are 2 versions to this game. The $5.99 version is the travel version.)

Very simple to press and children can have many hours of fun pressing on the Hippo's tail to try and catch as many colored balls as they can. Whoever catches the most wins! This game works on motor skills.

6

ROCK, ROLL, AND RIDE TRIKE



—18 months to 5 years

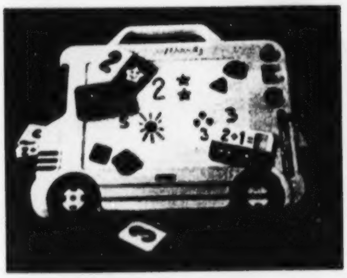
FISHER-PRICE--$32.99

This toy can be adapted dependent on a child's level of skill. First, the toy can be placed on a glider, and with little movement, the toy can be rocked, similar to a rocking horse. Just the action of getting on and off can enhance motor planning skills.

This is wonderful for a child who is ready to explore his or her ability to move in an upright position. Good sitting balance is required, but not the bilateral integration skills required for pedaling a riding toy. When a child is ready for more movement experience and to help stimulate development of bilateral integration skills, the child can learn to pedal with the assistance of an adult pushing the toy from behind with a special handle. The handle can be removed so that the child can pedal independently.

12

ADD/ADHD



MAGNA DOODLE LEARNING BUS

—3 to 7 years

FISHER-PRICE--$21.99

Using this magnetic drawing bus, children can learn by tracing, drawing, or using stamps. The ten learning cards can be lifted off the bus, and a picture appears. The cards can be used as stencils for combinations of pictures. The magnetic pen lets children draw anything they want. Comes with three magnetic stampers. Good for fine motor skills.

10

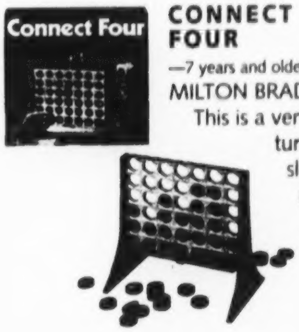
PLAYSKOOL SIT AND SPIN

—1 to 6 years

PLAYSKOOL--$24.99

Good for children with many physical disabilities, balance problems, hearing, speech, and visual disabilities. Child must have some upper body strength and be able to sit. Especially good for children with ADD

9



CONNECT FOUR

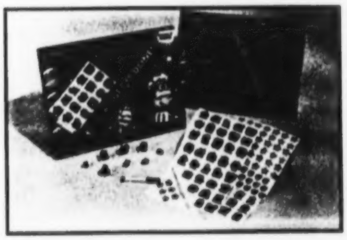
—7 years and older

MILTON BRADLEY--$14.99

This is a vertical checkers game. Players take turns dropping the chips into the slots and the first to complete a row, wins. Does not focus on any written instruction.

1, 7

GLIRBLES GET IT DONE! JOB & REWARD CHART



—4 to 8 years

INNER WORKS--$14.99

Make progress and rewards more tangible with this simple, visually interesting charting tool. After agreeing to a reward for having performed some positive behavior, celebrate each time the child succeeds, and post one more star on his chart. Your child will have a tangible record he can look at to see how he is doing, and what he needs to do to achieve his reward.

4

ADD/ADHD

SUN AND SHADE SANDBOX

(not pictured)—12 months to 5 years

LITTLE TIKES--$49.99

The overhead canopy on this sandbox helps to shield children from the sun. The wide, rounded edge provides a place for children to sit. Toys can be hidden in the sand for added fun. **10**

LITTLE SMART SING N' SMILE PALS

(not pictured)—0 to 3 years

V-Tech--$24.99

Press the buttons in front of any of the four animals and they will tell what kind of animals they are. The toy ligths up as well as plays music and silly sounds. **5**

PRETEND & PLAY TEACHING TELEPHONE

—3 to 8 years

LEARNING RESOURCES--$39.95

This is a bright, electronic phone with large buttons 11 digit keypad, and pre-recorded messages . The phone is programmable, so parents can enter phone numbers they want their children to learn, and record personalized messages that will play when the number is dialed correctly. This toy encourages speech through pretend play **10**

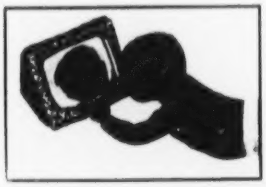
THINKWORKS SMART READERBOOK & CARTRIDGE

(not pictured)—4 to 8 years

TOYMAX--$9.99

Available with many different sories (Dr. Seuss, Arthur, Little Bear), this talking book reads the story, and then children can play games to see how much information they have retained. There are color codes from the book that can be input into the Smart Reader to learn new words. This toy works on language comprehension skills. **10**

SUITABLE FOR ALL CATEGORIES



LAMAZE FIRST MIRROR

—0 to 3 years

LEARNING CURVE--$19.99

Children enjoy seeing their own reflections. This triangular wedge stimulates children's vision with high contrast colors while providing their favorite image. The foam acts as a base for the mirror, which can be attached to the sides with Velcro. Detach the mirror and use the wedge alone to prop up baby. The Velcro straps can also be used to hang the mirror from a crib or playpen. **5**

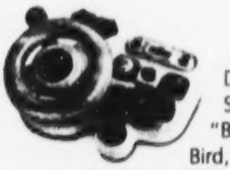
SPARKLING SYMPHONY XYLOPHONE

—0 to 3 years

FISHER-PRICE--$14.99

This toy will stimulate your child with two sides of musical play. On either side, keys or buttons are pressed for "sparkling" sound effects and lights; the musical bar makes the lights dance as a tune plays. Requires 3 AA batteries. **5**

ELMO'S TALKING DRIVER



—0 to 3 years

FISHER-PRICE--$19.99

Driving is fun with the help of your Sesame Street pals. Press Elmo to hear, "Beep beep coming through." Hear Big Bird, Cookie Monster, and Ernie encourage your child with a fun phrase. It also features realistic car sounds, flashing lights and music as well as a working steering wheel. Requires 3 AA batteries. **5**

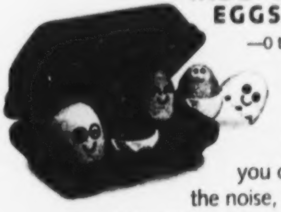
HAPPY PALS POP-UP PETE

—0 to 3 years

TOMY--$10.00

Pop-up Pete is a brightly colored boxer. This appealing character features a telescoping neck that makes a whistling sound, and easy to stretch and bend accordion arms are topped with twirlable oversized red boxing gloves. **5**

HIDE 'N SQUEAK EGGS

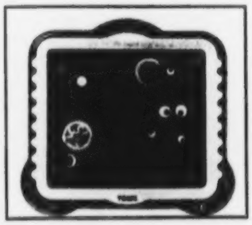


—0 to 3 years

TOMY--$9.99

Open up their hideaway and find six smiling eggs that "cheep" when you press down on them. When you open the eggs to see who's making the noise, they reveal six variously colored chicks. Encourages in/out, on/off sorting. **5**

GEARATION



—0 to 3 years

TOMY--$19.99

Put 11 wild neon, turning, rotating, goofy gears together on a battery-operated magnetic surface and watch as the gears flip, turn, chime, and fascinate. Turn it on and add the first gear to the magnetic surface. Control the speed with the fast/slow button or change the direction with the forward/reverse mechanism. Requires 1 C battery. **5**

SUITABLE FOR ALL CATEGORIES

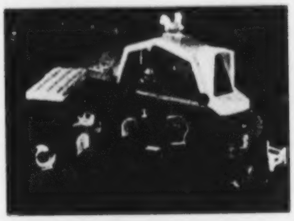
LITTLE PEOPLE FARM

—0 to 3 years

FISHER-PRICE--$34.00

The farmer and animal figures encourage dialogue and vocalization. The barn opens to reveal stalls, swinging gates, feeding bins, a drop-through chute, and a chicken's nest in the hayloft. Parents can help their children make up stories and learn animal sounds.

5



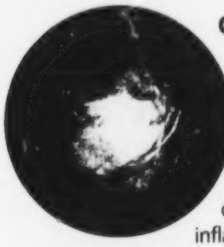
STUDIODESIGN EASEL

(not pictured)—2 to 7 years

LITTLE TIKES--$39.99

A durable and colorful easel. The storage trays are large and able to hold plenty of supplies. The paper pad is held to the easel by a large clip. The tray can be removed for wheelchair access.

5



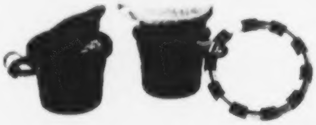
GERTIE BALL

—3 to 7 years

SMALL WORLD TOYS--$4.99-$9.99

The Gertie Ball is easy to catch and grip. It has a soft, semi-"sticky" surface. The non-toxic surface is soft and flexible, but does not withstand biting! Play kickball or catch--even in the house. The Gertie ball inflates easily through a straw and deflates just as easily. This ball comes in several varieties and sizes.

5



STACKING CUPS

—0 to 3 years

SASSY--$5.99

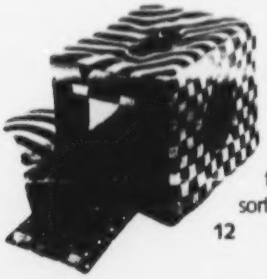
These colorful stacking cups are durable and textured. They can fit inside each other or be stacked one on top of another. Use them for snacks, to hide small objects, or just bang them together. 5

LAMAZE SOFT SORTER

—6 months and up

LEARNING CURVE--$19.99

This shape sorter can be used for a variety of purposes, to enhance a variety of skills. It seems to have been designed to provide a wide range of sensory experience. Each shape is textured both by material and color, stimulating the sense of touch and vision. The shapes are large enough to accommodate a variety of grasps and do not require the precision demanded by other shape-sorting toys. Both the shapes and the sorter are soft and flexible, allowing for trial/error exploration and increased chance of success. Contrasting colors and designs can help guide the child to place the shape into the sorter. Each shape also makes a different sound when grasped, stimulating t1he auditory system. The shapes can be easily retrieved through the Velcro closure top. This toy is also good for children who have just entered the "dump and fill" stage. Shapes and sorter are both machine-washable.



12

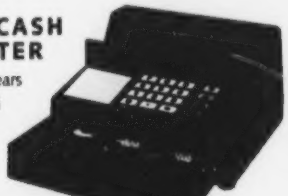
HEARING/SPEECH IMPAIRMENT

SEA LIFE PAT MAT

—6 months and up

BATTAT--$9.99 [Many different pat mats are available from other companies as well]

Pat mats are mats that, when filled with water, have shapes that move around freely within the mat. When full, the mat looks like a pillow. Patting the mat, even gingerly, or lying on the mat, causes the shapes to move around in the water. This is a great toy for working on cause and effect. Because one side of the mat is clear, these shapes are easily observed and are often contrasted by colorful or black and white shapes at the bottom of the mat, stimulating the visual system. Dependent on what shapes are in the mat, other skills can be worked on as well. Some mats are filled with letters or numbers, which can enhance early visual recognition and visual memory of numbers and letters. This toy is washable and easily transportable. 12



PRETEND & PLAY CASH REGISTER

—4 to 7 years

LEARNING RESOURCES--$39.95

Kids love to pretend. With this cash register, they can communicate using dialogue they are already familiar with, having accompanied mom to the store. Set up play situations with real food, encourage the naming of objects as they pass by. More useful communication happens with the identification of numbers and money. 4

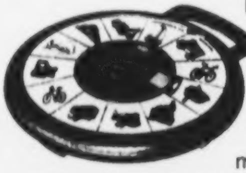
BUTTERFLY GARDEN

—6 to10 years

INSECT LORE--$19.99

Let your children watch life unfold before them, as caterpillars transform into butterflies. Parents report that their children are entranced, visiting their butterfly garden each day to see what happens.

4



LEARNING CIRCLE-THE MATCHING FUN GAME

—3 to 6 years

EDUCATIONAL INSIGHTS--$29.99

Lights and sounds guide the way in a series of interactive games. The light moves around the circle and stops next to a certain object. The child then tries to match it with the correct object. Successful matches result in a musical reward.

1

COUNT YOUR CHICKENS!

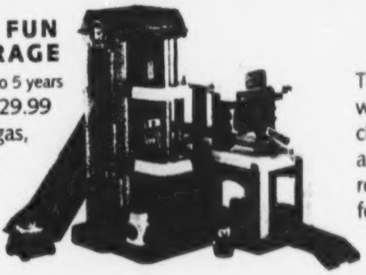
(not pictured)——3 to 6 years

CARPE DIEM GAMES--$9.99

A number-themed card game that lets children practice counting, matching , and simple math. The deck features animals on various types of transportation.

1

HEARING/SPEECH IMPAIRMENT



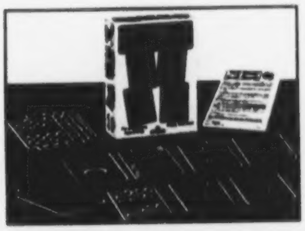
LITTLE PEOPLE FUN SOUNDS GARAGE

—18 months to 5 years

FISHER-PRICE--$29.99

Children can fill up toy cars with gas, go through the car wash, or have repairs done. Garage has three levels with ramps, elevators, and car lifts. The gas pump rings, the horns honk, and the tools make realistic sounds. A long ramp with a hidden door sends cars rolling quickly down from the top levels. Using toys that make noise are appropriate for children with hearing loss, and encourage listening.

1, 11



TODD PARR: THE OKAY CARD GAME

—5 to 9 years

INTERNATIONAL PLAYTHINGS--$8.99

Using the artwork of Todd Parr (author of the "Okay" books) this is a memory game for everyone. Children who cannot read can play with those who can. The stick-figured drawings are easy to understand, and children are taught that lots of things are "okay" from having freckles to wearing a fish in your hair.

1

PLAYSKOOL TAPE RECORDER WITH SING-A-LONG MICROPHONE

—3 to 7 years

KID DESIGNS--$29.99

Tape recorder lets children listen totheir favorite songs, and with the microphone , they can sing along and record their voices. Recorder has color-coded buttons with large symbols for easy use. Playback mechanism let s child hear his/her own speech. Also appropriate for children with ADD/ADHD.

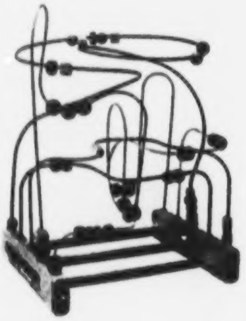
10

BALL PARTY: ROLL AROUND TOWER

—12 months to 4 years

TOMY--$19.99

The balls are different colors that can be taught first for receptive language and encouraged at older ages as expressive language. The toy encourages exploration of cause and effect. The balls are put into the top of the toy and go round and round making a whirring sound as they go. Encourage your child to listen for the sound. Young children love the repetitive nature of this toy. 11



THE ROLLERCOASTER

—18 months to 5 years

ANATEX--$49.99

This toy is seen in every play area where you find children. Young children are fascinated by the loops and spirals the beads make as they go round and round, and can play with it for a long time. The language you can teach are names of colors, counting, up and down and all around. Let your imagination run away with ideas of cars on the road, trains on the track, or children walking to school. Make up stories as you play. 11

MERCER MAYER'S LITTLE CRITTER: JUST ME AND MY GRANDPA

(not pictured)—3 to 8 years

INFOGRAMES--$19.99

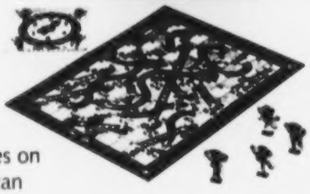
CD-ROM story that helps teach memory skills, reading, and learning about all of the activities that take place on a farm. Includes 12 illustrated pages and 6 games. Encourages speaking. 1

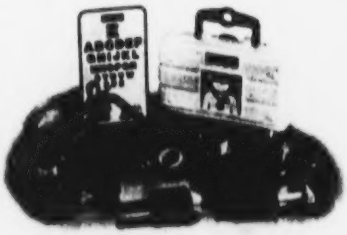
CHUTES AND LADDERS

—4 to 7 years

MILTON BRADLEY--$7.99

There is no reading required and the rules are simple, which makes a good beginning game for children to learn about taking turns and winning and losing. It is an excellent game for introducing numbers in a fun way. For younger players the parent can say the numbers for the child as he or she advances on the board. Using listening alone can enhance auditory skills. 11





MEDICAL KIT

—3 to 7 years

FISHER-PRICE--$9.99

Children with special needs spend lots of time at the doctor, therapist, or specialist. A medical kit is a way for them to be in charge and to have their "patient" respond to their commands. It is also an excellent way to prepare for a visit to the doctor. The parent can teach the language of each of the pieces of equipment and what procedure will be done. There is an eye chart, which helps to teach the letters of the alphabet as well as prepare the child to have his/her eyes tested. 11

LEARNING DISABILITIES

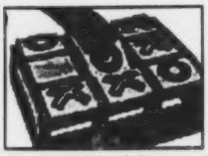
FUN WITH YOUR DOG
A SCIENCE KIT

FUN WITH YOUR DOG -A SCIENCE KIT

—9 years and older

SCIENTIFIC EXPLORER--$19.99

Good for children who have difficulty understanding other people's emotions. Use the family dog as a starting point to talk about and interpret what other animals feel. This kit helps your child look for cues, to understand what certain actions or sounds mean about your dog's behavior. Also see Fun With Your Cat – A Science Kit. **4**



TOSS ACROSS

—5 to 9 years

MATTEL--$19.99

This is a tic-tac-toe game in which you throw bean bags , and try for three in a row. X's and O's change as they are hit with the bean bag. Good for eye-hand coordination, which is a skill that is sometimes underdeveloped in people with learning disabilities. **7**

TWISTER

—6 years and older

MILTON BRADLEY--$14.99

Each spin of the dial requires a player to place a hand or foot onto a different colored circle printed on the vinyl game mat. As the game progresses, it becomes increasingly difficult to maintain balance. A fun way to work on gross motor skills. **7**

SCRABBLE JUNIOR

—5 to 10 years

MILTON BRADLEY--$9.99

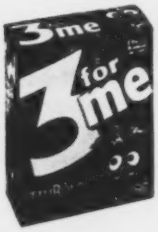
Game has two skill levels. At the first level, players match letters to illustrated words on the board. More advance d players make up their own word using the blank squares. Uses visual skills. **7**

TRI-BOND

—9 years and older

PATCH PRODUCTS--$24.99

This game presents players with three things, and players must figure out what they have in common. After making a connection, players advance along the board. Cards can be used alone to play on trips in the car. This game helps with language skills as well as finding relationships. **7**



THREE FOR ME

—4 to 7 years

PATCH PRODUCTS--$8.99

This game is very much like Tri-Bond, but for younger children. Players look through the pictures to find three with a common bond. When found, the three pictures are removed. As more pieces are removed, players must be more and more creative to find common bonds in the remaining pieces. **7**

I SPY
EXTREME CHALLENGER!

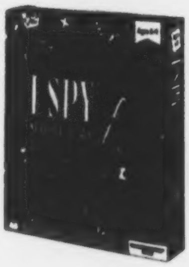
I SPY SUPER CHALLENGER!: A BOOKOF PICTURE RIDDLES

—4 to 8 years

by Jean Marzallo, photgraphed by Walter Wick

SCHOLASTIC, INC.--$12.95

A picture riddle book that contains a variety of hidden objects on every page. Riddles refer back to objects on pages earlier in the book, and children are encouraged to make up their own rhymes and riddles. **7**



I SPYSCHOOL DAYS

—5 to 9 years

SCHOLASTIC--$29.95

The newest CD-ROM version of the picture riddle books. This CD-ROM includes hundreds of puzzles and riddles that help develop skills in vocabulary, rhyming, memory, creativity, sorting, and problem-solving. Contains nine themed areas and more than 1600 object and word searches. **7, 11**

PERFECTION

PERFECTION

—5 years and older

MILTON BRADLEY--$16.99

A fast-paced, fun game. The object is to get all 25 shapes into their matching holes before the 60-seconds are up, and all of the pieces pop back out. Develops skills in identifying and matching. **1**

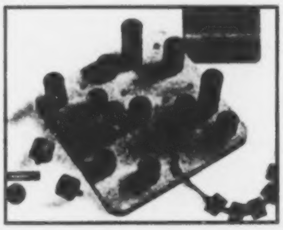
THINKIN' THINGS

THINKIN' THINGS: SKY ISLAND MYSTERIES

—8 to 12 years

EDMARK--$27.99

Help Inspector Cluestoe solve 14 different mysteries and catch the perpetrators. Works on decision-making, prioritizing, and problem-solving. This game combines learning and fun and teaches communication using a variety of words along with pictures. Has self-adjusting skill levels. **1**

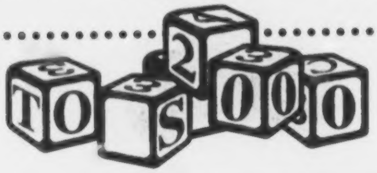


GIANT PEGBOARD TOY

—1 to 6 years

DISCOVERY TOYS --$12.99

Sometimes, the simplest toys are the best. Go from stacking pegs (pre-counting skills) to color sorting and pattern recognition. Comes with a parent guide filled with lots of ideas to keep things fun for years to come. **4**



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3. **Eric Rose**, United Cerebral Palsy of NYC Children's Program, Bronx, NY.
4. **Fred Tchang, ATP**, Director of Rehabilitation Technology Services, United Cerebral Palsy Associations of New Jersey, Trenton, NJ.
5. **Let's Play! Project**, Center for Assistive Technology, State University of New York at Buffalo, NY: Susan Mistrett, MS, Ed, Project Director; Amy Goetz, MS, OTR/L, Project Evaluator; Shelly J. Lane, PhD, OTR/L, FAOTA.
6. **Jamie E. Sowers**, parent of two children: Ryan, 7, and Rebecca, 10. Rebecca has cerebral palsy.
7. **Ronee Groff**, parent and advocate; **Bonnie Zimmerman, MS-CCC/SLP, Fran Newman, OTR, Billie Stein, OTR, Frank Matalavage, PT, and Kathy Huenke, PT**, Atlantic County Special Services School District.
8. **Marlena Thompson**, parent of a teenage daughter who has autism.
9. **Suzanne Ripley**, Director of the National Information Center for Children and Youth with Disabilities (NICHCY),and parent of two sons with multiple disabilities.
10. **Lauren Agoratus** of NJ State and Maternal /Child Health Coordinator for Family Voices and NJ Coordinator for National Family Caregivers Association, Allentown, NJ and parent of a child with Asperger syndrome.
11. **Susan Schwartz, PhD**, co-author of the book, *The New Language of Toys*
12. **Deborah R. Labovitz, PhD, OTR/L, FROTA**
Professor and Chair of the Department of Occupational Therapy at New York University.
13. **Mary Ann Siller, MEd**, Co-Chair of the National Education Programs for the American Foundation for the Blind, Southwest

RESOURCES: TOY MANUFACTURERS & CONSUMER INFORMATION

Most of the toys included in this article are available at retail stores or on the Internet through the manufacturers' Web sites (see below) or On-line toy stores like http://www.etoys.com, or http://www.kbkids.com. Contact the following manufacturers for more information on product availability. (Remember if ordering toys for the holiday sesason to leave ample time for delivery.)

Alex Toys
Web site: http://www.alextoys.com
Phone: (800) 666-2539

Anatex Enterprises
Web site: http://www.anatex.com
Phone: (818) 908-1888

Battat
Web site: http://www.battat-toys.com
Phone: (800) 247-6144

Briarpatch
Web site: http://www.briarpatch.com
Phone: (800) 232-7427

Carpe Diem Games
Phone: (781) 944-2838

Discovery Toys
Web site:
http://www.discoverytoysinc.com
Phone: (800) 426-4777

Edmark
Web site: http://www.edmark.com
Phone: (425) 556-8400

Educational Insights
Web site:
http://www.educationalinsights.com
Phone: (310) 884-2000

Fisher Price
Web site:
http://www.fisher-pricestore.com
Phone: (800) 432-5437

Hasbro
(Playskool, Parker Brothers, Milton Bradley, Oddzon, and Tonka)
Web site: http://www.hasbro.com

Hedstrom Corporation
Phone: (800) 233-3271

Inner Works
Phone: (888) 868-7883

Insect Lore
Web site: http://www.insectlore.com
Phone: (800) 548-3284

International Playthings
Web site: http://www.intplay.com
Phone: (800) 445-8347

Kid Designs
Web site: http://www.kiddirect.com
Phone: (888) 867-8697

Knowledge Adventure
Web site:
http://www.knowledgeadventure.com
Phone: (800) 545-7677

Learning Curve
Web site:
http://www.learningcurve.com
Phone: (800) 704-8697

Learning Resources
Phone: (800) 222-3909

Lego Systems, Inc.
Web site: http://www.lego.com
Phone: (800) 453-4677

Little Tikes
Web site: http://www.littletikes.com
Phone: (800) 321-0183

Living & Learning
Phone (800) 306-3013

Mattel
Web site: http://www.mattel.com
Phone (800) 524-8697

Maui Toys
Web site: http://www.mauitoys.com
Phone: (310) 575-4111

Patch Products
Web site:
http://www.patchproducts.com
Phone: (800) 524-4263
(608) 362-6896

Razor
Web site:
http://www.razor-scooter.com

Sassy Toys
Web site:
http://www.sassybaby.com
Phone: (616) 243-0767

Scholastic Inc.
Web site:
http://www.scholastic.com
Phone: (800) 242-7737

Scientific Explorer
Web site:
http://www.scientificexplorer.com

Small World Toys
Web site:
http://www.smallworldtoys.com

Sport Fun
Phone: (800) 423-2597

Tomy Manufacturing
Phone: (949) 955-1030

Toymax International
Web site: http://www.toymax.com
Phone: (800) 222-9060

University Games
Web site:
http://www.areyougame.com
Phone: (800) 471-0641

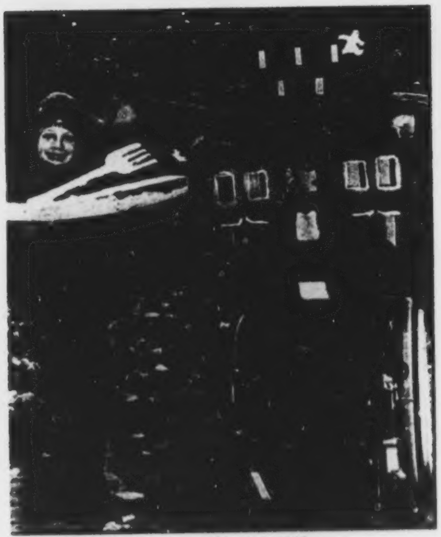
VTech
Web site:
http://www.vtechinc.com
Phone: (800) 521-2010

1111

The Witching Hour

Inexpensive, Creative Adaptive Halloween Costumes

As we do each year, EP has asked readers to share their answers to that age-old question, "What are you going to be for Halloween?" This year's submissions feature costumes that consider cost, safety, and suitability to children with a variety of disabilities. Check our Web site: http://www.eparent.com, for more costume ideas. We thank all the parents for relating the joy these costumes brought to their children. Have a ghoulishly good time!



Jake Kaplan (r.) and his sister, Abbe.

The Haunted House

by Lauri Kaplan

Materials:

- One large and one small cardboard box
- Long, miscellaneous pieces of cardboard
- Wide paper tape—available in paint or hardware stores
- Spray paint, markers, glow-in-the-dark paint
- A "spooky music" tape and tape player

Jake Kaplan, who has corticallblindness and receives nourishment from a g-tube at night, uses a wheelchair that has a tray fitted to the front. To make the house, his mother took a large square cardboard box that could "sit" on his tray and would be tall enough so it would not touch her son's head as he was inside the box. To make the attic, or second floor, she taped another, smaller box to the top, and the roof was made by taping more cardboard (as flaps) to the front and back of the big box. Holes were cut out for windows, and black and dark purple spray paint was used to decorate the house to make the doors and shutters and to give it a "haunted" feel. Ghosts, bats, etc., can be painted on with flourescent paints. Make this costume extra eery by having your child play the spooky music from a tape player that rests on his/her lap or tray under the house. Spooky music tapes can be found at the library or in novelty stores.

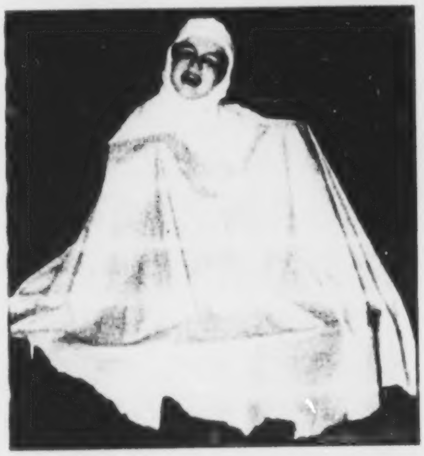
The Ghost

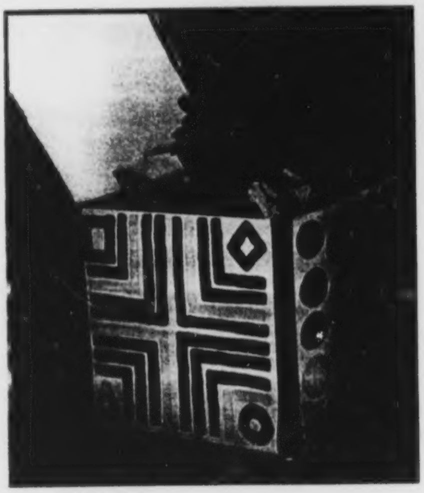
by Bev Sargeant

Materials:

- a tricycle
- a white sheet and stocking cap
- a hula hoop
- strong string or small rope
- 2-sided tape
- scissor

Erik (who was 3 years old when he wore this costume) has cerebral palsy. His parents decided to use his adapted tricycle to create the illusion of a ghost whisking through the air! (To adapt his tricycle, specially manufactured foot plates with straps to keep his feet in place were attached to the bike pedals. An engineer at Erik's therapy center came up with the idea of a wooden seat with a back for stability and a belt for his torso.) The sheet is kept away from the tricycle by attaching a hula hoop to the center bar of the bike frame with ropes. Use the on the front and sides of the hoop where the sheet touches so that only the back of the sheet will fly around when your child pedals. The hood is simply a stocking cap that can be bought at a department store. Cut out a hole for the face to make seeing easier when your child turns his/her head side to side. The tricycle can be any kind at all, adapted or not, as long as the hula hoop fits around it.





The Jack-in-the-Box

by Bev Sargeant

Materials:

- A stocking cap
- Many colored fabric remnants
- Glue
- Pieces of colored yarn
- Small bells
- Small string
- 1 paper towel roll and 2 toilet paper rolls
- Spray paint
- Tape
- Scissors
- A clothes hanger (optional)

continued on page 34

continued from page 33

Decorate a stocking cap and any other old clothes with fabric remnants. Decorate the rest of the costume by spray-painting the box and cutting more remnants into diamond shapes and folding them in half to form triangles. Put bells on short pieces of yarn and glue the yarn into the points of the triangles. Glue down the sides of the triangles. To make the crank on the side of the box, tape together the paper towel and toilet paper rolls and spray-paint them black. You may have to cut the rolls at an angle to get them to fit together better, and fit them into the box by cutting a hole in the side. You can also put them onto a bent clothes hanger and poke the hanger through the box. Take care to cut the slits properly in the back of the box so that the wheelchair handles can slide through.

DANGER
WILD ANIMAL

The Dangerous Animal

by Bev Sargeant

Materials:

- panther mask or make-up kit
- black clothes (sweatpants and long-sleeve shirt)
- black mittens
- plastic witch's fingernails
- a large cardboard box

You can either buy the panther (or any other animal) mask or use one of the many make-up kits available in novelty stores. Dress up your child in the clothes. Poke the witch's fingernails through the mittens. Cut rectangular holes out of the sides of the box so that it looks like bars (this actually makes it a little easier to place over the stroller). Dress up the person wheeling your child as the animal's trainer!

Tarzan

by Betsy Holquist (from the Bridge School: http://www.bridgeschool.org)

Materials:

- Chicken wire
- Light-weight rope (approx. 8 feet)
- Poster paint—brown, nontoxic
- Plastic vine
- An assortment of live or plastic ferns, leaves
- Green felt
- Watered-down white glue
- Tarzan costume
- Rubber lizards and snakes and/or stuffed pet monkey (optional)
- bungy cord
- Newspaper

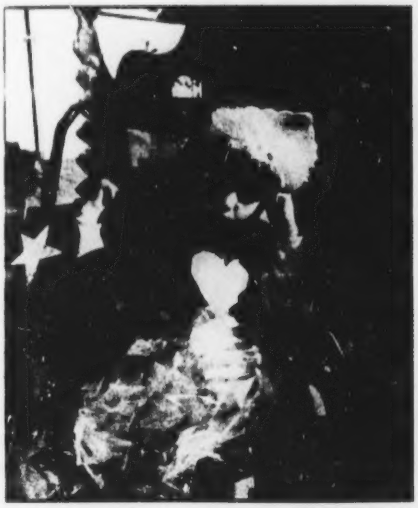
Form the tree trunk and branch out of the chicken wire. Attach the branch through a hole in the trunk and fasten them together with smaller pieces of wire. To make the swinging vine, tie one end of the rope to the base of the trunk and feed it through the tree to the end of the branch. Let it dangle from the branch and decorate with the ivy. Next cover the chicken wire by dipping strips of newspaper in the watered-down glue and wrapping the trunk and branch of the tree. You may need two layers. When dry, paint. (You may also want to stain the vine rope.)

To finish off the "jungle," cover the wheelchair with the felt and decorate everything with the ferns and leaves. Accessorize with the fake animals (optional). Tarzan costumes are widely available, as is fake fur in craft or fabric stores. Another fun addition to this costume is having the user play Tarzan music on a hidden tape player.

Fairy Princess

by Angie Power

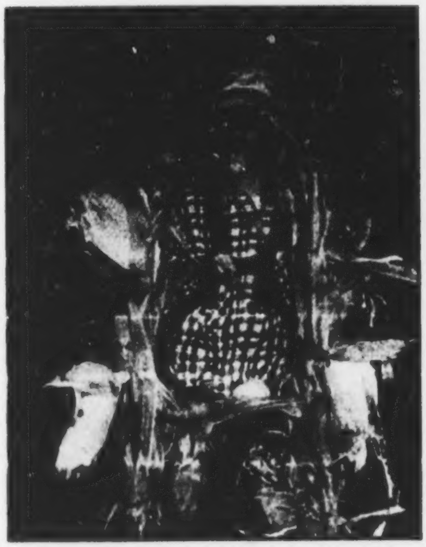
This past summer, Willow Power, 7, (who has severe brain damage as a result of contracting pneumococcal meningitis at age 7 months, and, as a result, is nonverbal, with visual impairment, epilepsy, and spastic quadriplegia) participated in a costume party held by her recreation group. Her mom, Angie, and Aunt Zoe put together this costume, which suited Willow just fine in her wheelchair. Use cardboard, paint, and glittery contact paper to make the throne for the back of the wheelchair. (Tape or tie on the sides to allow your child who may not be able to turn her head to see the throne.) Make the costume by sewing irridescent fabric in strips to a ribbon waistband. Tie it in the back like an apron so it can be removed easily. They are also widely available in stores. Don't forget the glitter on the face!



The Scarecrow

by Bev Sargeant

Craft stores carry the loose straw and corn stalks that you will need for this costume. Extra-long clothing can be used to make the feet and hands look like they are made of straw. Ensure that they do not drag on the ground or catch in the wheels. Duct tape can be used to keep everything together. ■



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Circle #53

THE POWER OF PLAY

By Sarah N. Paweni and David Rubovits

Playing is not just fun for a baby but for the whole family! Here a Lekotek family enjoys playing with a doll, delighting in the tactile and visual stimulation it provides.

Play takes place at school, in parks, at daycare sites, in early intervention programs, in therapy sessions, and especially at home. Toys help with the real work of stretching muscles, improving coordinated reaching, and learning to read.

For any child, the full benefits of skill-building play occur if the play environment and materials are suited to the child's developmental level and abilities. For children with disabilities who may require adaptations or modifications, access becomes the critical issue.

Access to play opens up numerous doors for children with disabilities. Those doors are located in homes as well as schools, recreational settings, childcare sites and early intervention programs. Adequate access to play allows parents to increase their expectations of their children's abilities. When a child has access to toys and games, it is easier to move beyond the discourse of deficits—what he or she cannot do—and to observe, reinforce, and marvel at what he or she can.

The by-products of play and toys are enjoyment, sharing, attachment, and modeling, which are important for all children. Children are probably the best teachers of play. Not only are they good at it, they are genuinely excited about sharing play experiences with other people—especially parents and siblings. Children with disabilities are no different. In fact, it may be even more exciting for children with a disability to demonstrate and teach their play skills, because then they are leading the activity and providing the expertise. In that way, play (when accessible) is a great leveler and a wonderful tool for family interaction.

The National Lekotek Center is dedicated to making play accessible for all children by applying both the science and art of child development to promote developmentally appropriate play and learning opportunities for children with special needs and their families. Lekoteck offers the following ten tips to consider when selecting toys for your child, regardless of his/her disability:

1. Opportunity for multi-sensory appeal/stimulation.
2. Easy/simple method of activation.
3. Setting in which toy will be used (indoors, outdoors etc.).
4. Opportunities for success.
5. Current popularity among other kids.
6. Promotion of self-expression.
7. Easy adjustability.
8. Suitability for the child (fits your child's individual characteristics and interests).
9. Safety and durability.
10. Potential for appropriate social interaction.

Following are some things to consider when choosing toys for specific disabilities:

Physical Disabilities

- Suction-cup-based toys to aid stability (rattles, balls and mitts with suction cup bases);

Lisa and Katelyn Klepitisch show off their art project to Lekotek play expert Rebecca Krook as her mother, Kristen, looks on.

1115

A doll brightens the world of play for Jimmah Allen, 8, who has cerebral palsy, and her mother, Tauheedah.

- Variety of textures for exploration and stimulation (puzzles with textures, balls with nubs, bristles, etc.);
- Enlarged handles for easier grip/grasp (paint brushes with large handles, toys with large knobs);
- Attachment straps (toys with straps to attach to hand or play surface);
- Sustained action (ball trackers, spinning tops, keyboards);
- Adjustable height to meet the child's needs (basketball net, T-ball).

Visual Impairments

Children with a visual impairment learn about the world around them from the use of other senses (touch, taste, smell, hear). In general, talking to your child about the various activities in which you are both engaged through the course of a day will encourage your child to explore. Some features to consider are:

- Varying auditory cues, vibrations and noises (music boxes, tape recorder, toy instruments);
- Open-ended activities (activity sets, flannel board with shapes, numbers and letters);
- Bright, high-contrasting colors;
- Tactile exploration and interest (squeeze toys, cuddly toys, balls, floating water toys);
- Imaginative and creative play (cook sets, tool sets, dolls and puppets);
- Large or easy to activate knobs and handles.

Hearing Impairments

For a child with a hearing impairment, play provides a wonderful way to introduce the world of language. Simple, one-word interaction or instructions will help the child learn to associate speech and body language with communication. Features to consider include:

- Wide variety of visual attraction with bold and fun colors (busy boxes);
- Tactile interest and exploration (clay, puzzles with textures,cuddly toys);
- Differing scents and smells (scented balls or clay);
- Adjustable sound or music levels (musical toys, toy instruments);
- Variety of sensory stimulation, like lights, vibrations, and sounds.

Learning Disabilities (LD)

Children with learning disabilities often have difficulty listening, speaking, reading, spelling, or doing mathematical calculations. They also have different learning styles: visual, auditory, or kinestic (learning through movement or by doing). Pick toys that match your child's learning style and consider the following features:

- Simple design (puzzles with one color background, simple pictures in books, simple game boards);
- Short game duration (games that have variations or modes of play or quick playing time);
- Concrete as opposed to abstract pretend play (puppets of real people or animals, pretend play food);
- Clear cause and effect (electronic toys that say a letter rather than music or word, toys with levers to press or turn for immediate response);
- Simple instructions (puzzles that have the same pictures on the piece and underneath, matching identical pictures);
- Versatility (varying levels/modes of play, electronic toys with several modes of play);
- Repetition (basketball hoops, electronic musical toys, push button cause and effect toys).

Speech and Language Delays

For children with speech and language delays, it is important for parents and children to enjoy play activities together. Remember, children learn best by doing and they learn more by handling objects and being actively involved in an activity rather than watching an adult do the same project. Some features to consider when choosing toys for children with speech and language delays include:

- Social interaction or group play (board games, see-saw, walkie-talkies, blocks, play phone);
- Pretend play activities that are similar to daily life (miniature kitchen appliances, cooking, driving a small car or truck, toy telephones);
- Concrete or familiar concepts and ideas (dolls);
- Responses/interaction required (tape recorder with microphone for sing along, computer-interactive read-along books);
- Creativity (art projects);
- Matching or pairing games.

ADD/ADHD

For children with attention deficit disorder (ADD) or attention deficit hyperactivity disorder (ADHD), it is important to limit distractions in the room; present toys or activities one at a time and give them full attention. Features to look for when choosing toys for children with ADD/ADHD include:

- Bold and contrasting colors that stimulate visual interest and exploration;
- Controllable or adjustable sound levels (radios, walkie-talkies);
- Open-ended activities with no right/wrong way of doing (sponge painting or hat painting sets);
- Partnering toys (i.e., basketball toys, board games);
- Physical activities (roller blades, street hockey, basketball toys).

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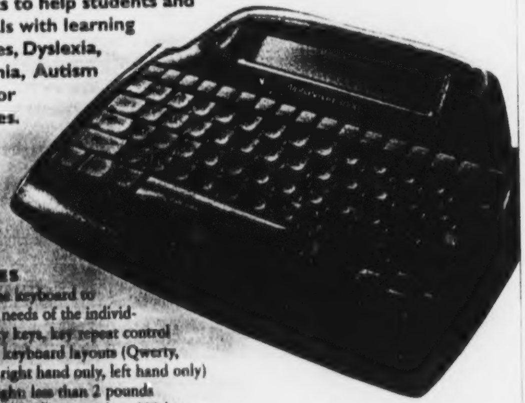

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Autism

Autism is a spectrum disorder that can encompass mild to severe social and language deficits. Consideration should be given to the child's possible sensitivities to touch and noise; select toys that are most appropriate for his or her needs. Here are some ideas:

- Singing and rhythm activities to encourage social skills (talking keyboard, talking magnets or talking stamps);
- Fine motor skills (flash cards or magnetic play sets);
- Realistic pretend play (animal puppets, battery-operated animated animals);
- Cause and effect learning or visual tracking activities (busy balls, marble runs);
- Problem-solving activities (matching games);
- Turn-taking or cooperative activities (parachute, bowling sets).

Katelyn Klepitisch enjoys a moment of fun in the red hot fire truck in Lekotek's play center.

Play is an activity for all children and all families—not just those without disabilities. Play heightens the focus on your child's positive capabilities, skills, and interests rather than his or her deficits. As a parent or caregiver, you can enjoy interacting with your child, at your child's level, with no outside criteria for success. Ultimately, it is these kinds of interactions that help parents and caregivers feel that they enrich the lives of their children and family. ■

Sarah N. Paweni is the Marketing Manager and David Rubovits the Director of Applied Research and Evaluation for the National Lekotek Center, Evanston, IL. Lekotek has over 60 affiliate sites across the country that promote access to play materials and technology (adapted if necessary), so that children with special needs can enjoy play and learning just like any other kids. To learn more about a Lekotek Center near you, or for more information call: The Lekotek Toy Resource Helpline (800) 366-Play (7259); E-mail: lekotek@lekotek.org; or visit their Web site: http://www.lekotek.org.

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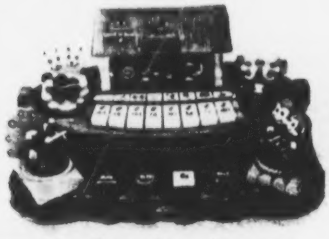

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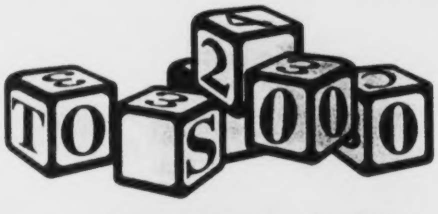
CHOOSING TOYS FOR A CHILD WITH AUTISM



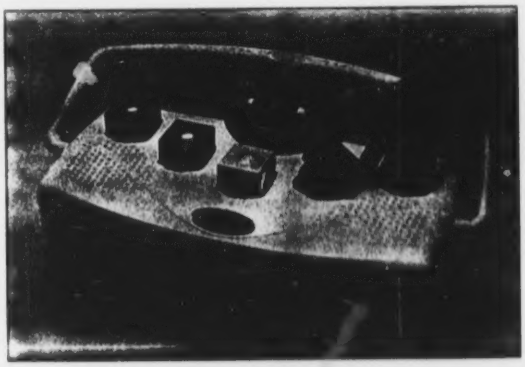
by Susan Senator

When my son was 11 months old, he went to his first birthday party. The birthday boy received a truck, a sing-along video tape, a learn-to-dress doll, and a ball. He was extremely excited about all of his toys, going from one to the other, squealing with the abandon only a baby can muster. I remember thinking, with a sinking heart, that my baby would not like any of those toys. I did not know he had autism at the time; I only knew that he didn't seem to like, or even notice, toys.

I have come a long way since those days of being mystified and heartsick. It hasn't been easy, but I have now figured out just what toys works for Nat and what toys don't. The following contains some toys that he has liked and some pointers for how I choose toys successfully for my child with autism:

DON'T PAY ATTENTION TO THE AGES LISTED BY THE MANUFACTURERS—EXCEPT IN TERMS OF CHOKING HAZARDS

If your child is developing atypically, as is the case with pervasive developmental disorder/autism spectrum disorders (PDD/ASD), then it doesn't matter if the box says: "ages 4 to 6" and he is 8. He may be ready for the toy at 8 or 10, but not before. What matters is getting your kid to play with something, to expand his horizons. Of course, parents should always pay attention to the choking warnings on products and keep in mind that children with autism may mouth things inappropriately, so small pieces may be a problem way beyond the usual age of 3.


Music Blocks by Neurosmith play a different song each time the blocks are shifted.

IF SOMETHING DOES NOT APPEAL TO YOUR CHILD, TRY IT AT ANOTHER PHASE OF HIS LIFE

The all-time best toy for my child actually was something that his friend got that day for his first birthday, but that did not work for my son until he was 4: Disney's Sing A Long Songs videos. These little gems are collections of songs from all the Disney movies, starting with "Snow White," going all the way to "Aladdin"; "The Hunchback of Notre Dame"; and "The Lion King." The predictability of a video along with the accessibility of song proved a magical combination for my son, and it happened much later for him than would be the case for a typical child. Animated videos were a very important communication facilitator for Sheila D., a Massachusetts mother of a boy on the autism spectrum. Her son's particular favorite (at age 3) was a video. One afternoon, Sheila noticed that "he kept doing something over and over...and saying this thing all the time. Then I saw him watching the video and I saw them saying this same thing. When I saw it I thought, 'That's where that came from,' and I tried it, I said exactly what they were saying... and he lit up! It was the first time we actually played together. We played it for about an hour."

EVEN IF YOU THINK YOUR CHILD IS BEYOND A PARTICULAR TOY, TAKE IT OUT AGAIN IN A FEW YEARS

When my son was about a year old, my sister Laura brought him a shape-sorter. This was a big red and blue polygon with different shaped holes cut into the sides, and about ten yellow shapes that would fit into the corresponding openings. This toy mildly interested our child when he was a baby. He would choose a shape and mouth it; I would then hold the ball and rotate it until the correct shape turned up, and I would help him slide his shape into the hole. This was a satisfying interaction for us.

But our use of the sorter did not end there. When my son was 7, part of his IEP (individualized education plan) was to learn shapes. After school, I would take out the toy and he could by then name the shapes and insert them himself. He loved this for the predictability, the tactile satisfaction of dropping the shape correctly into the hole, and for the way he felt knowledgeable about shapes.

Another infant-toddler toy that is particularly good for children with autism of any age is Music Blocks, by Neurosmith (562-296-1099). Nancy M., a mother of three from Philadelphia, loves this toy because it holds her son's interest for a while, yet is an appropriate toy because it utilizes sequencing and music. Music Blocks contains different musical cartridges that are inserted into the blocks, which are of different shapes. Depending on how you shift the blocks, the music played by the blocks varies.

TOYS FOR GROSS MOTOR DEVELOPMENT ARE A GOOD BET: SIT AND SPIN AND BICYCLES

Many children with autism enjoy a Sit and Spin by Playskool (800-724-7276) because they crave the spinning motion, and this is a way for them to satisfy this need safely and appropriately.

A far more common childhood toy that has worked well in our family is the bicycle, with and without training wheels. Nancy M. bought her son with autism a tandem attachment. This adapts a bicycle so it is like a tandem bicycle, enabling her son to peddle with her while Nancy does the steering and braking. Says Nancy, "He loves it. The family bike ride is something we can do now." Aside from the obvious benefit of getting some exercise—which can be crucial to some of these children who may become rather sedentary once they pass early childhood—there's the additional benefit of learning the rules of the road. Currently my son is working on paying attention to the "walk" and "don't walk" signs at intersections.

TRY THE OLD STANDBYS

Four very typical items have worked well for us: Candyland, puzzles, CDs, and books. Candyland by Milton Bradley (800-724-7276) is the simplest turn-taking board game, and most kids relate to the pictures of candy. I started with Candyland when my son was very young, and at first, I would take his turn with him, using hand-over-hand techniques as I moved his piece around the board. As he got older, he could turn over his own card and tell me what color square or what item was on the card—with prompting. By asking him what he should do next, and by repeating out loud what color he had picked, I was able to keep him focused on the game. One caution: Candyland has a lot of "go back to square one" kind of turns. This can be a problem with kids who have attention difficulties. If it takes too long to actually finish, then pick a reasonable ending point so that you can feel satisfied with what you've played. Or change the rules to suit your family. My rule is that you can't repeat the same "go back" more than once. It works better that way.

Jigsaw puzzles are an excellent leisure activity that help my

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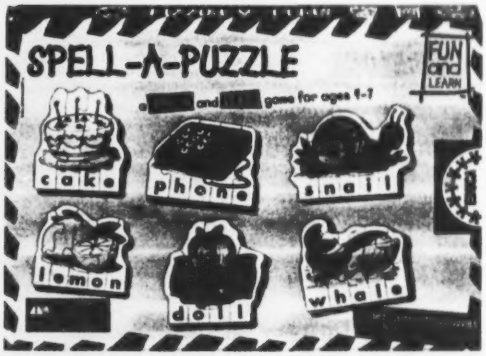

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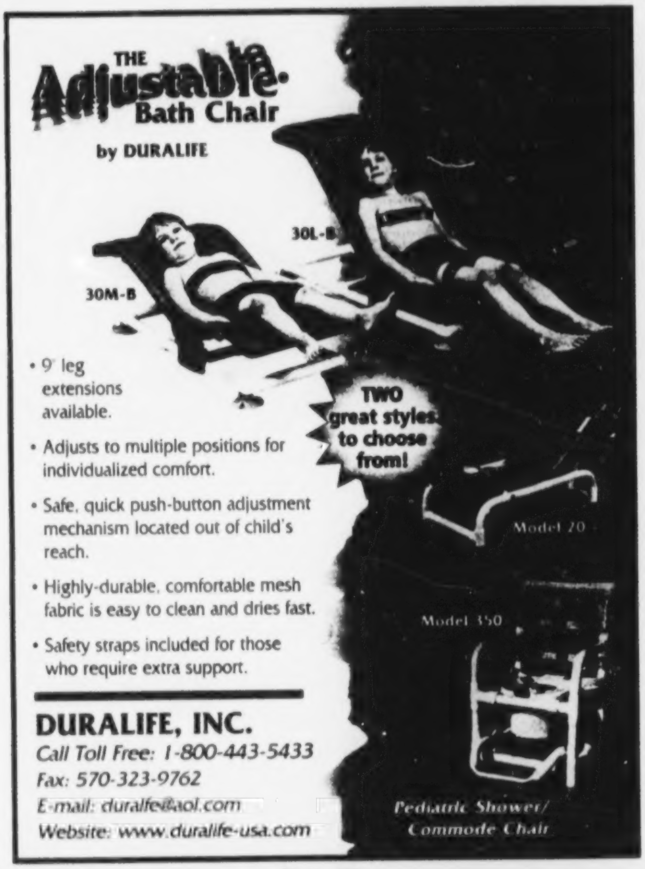
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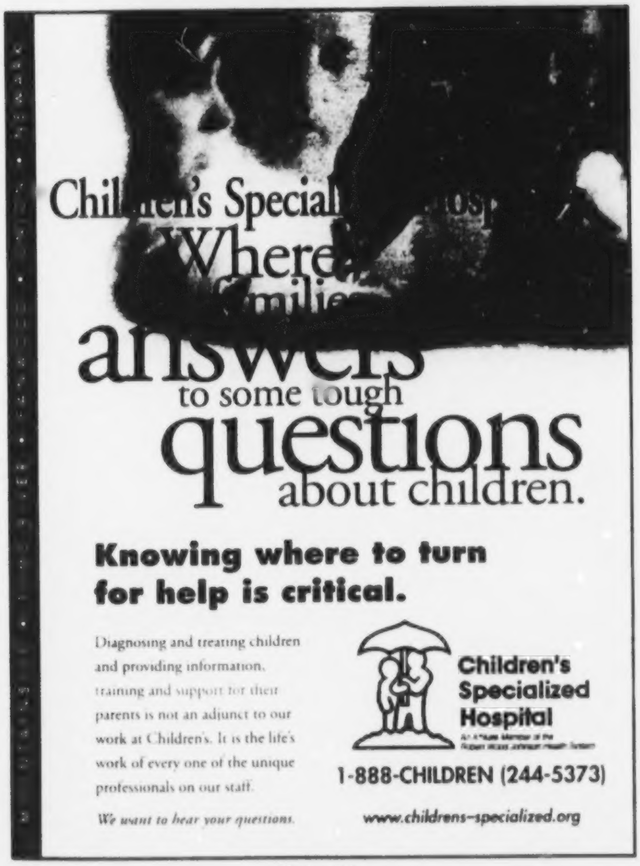

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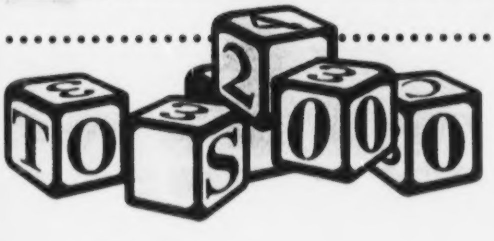

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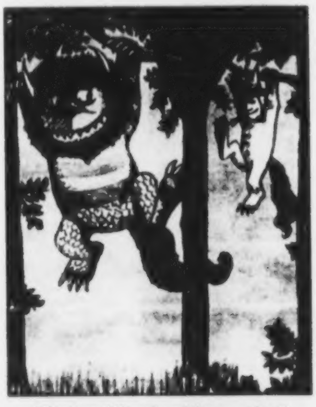
child feel confident. I started small, using the foam letter puzzles that had different surfaces which would interest his sense of touch. Then I moved up to more typical jigsaw puzzles.

The best puzzle I found for him actually taught him the concept of reading. It was an educational toy called Spell-A-Puzzle from International Playthings (800-445-8347). Spell-A-Puzzle contains about 20 small word puzzles, like dog, bird, and cake. When you put together the word puzzle, you also create the corresponding picture of the object spelled. This ingenious toy was successful because it puts together images with words and breaks the words up into letters, which can work very well for atypical learners who may not learn to read phonetically or as whole words. "Putting together the parts into the whole—the pictures and the letters—is a very successful way to grasp the concept of reading for atypical learners," says Beth Williams, a reading/writing specialist from Brookline Public Schools. "[This sort of puzzle] allows for a simultaneous presentation of a visual cue and the word," which can be extremely satisfying to a child with a learning disorder such as autism. And from a sensory perspective, occupational therapist Aneesa Usman points out that all puzzles provide some tactile feedback and satisfaction in the snapping together of the pieces. Kids with ASD and PDD often crave the "additional joint compression" provided by pushing at the pieces. This may explain why children like my son enjoy puzzles so much.

COMPUTER SOFTWARE

No list of toys for children with autism in the 21st century can be complete without covering computers. At age 6, my son first learned how to use a computer during occupational therapy sessions. The therapist wanted to improve his hand-eye coordination, and using a mouse was a good goal to that end. She started him off with a touchscreen, so that he could grasp the concept of sending commands to the computer with a touch. He quickly graduated to a mouse.

The software he began with was "Thinkin' Things," by Edmark (425-556-8400). The programs were very simple, asking him to identify which item was different from the rest, or matching programs. This coincided well with his IEP goals, and he thoroughly enjoyed the animation. He now enjoys a lot of different software, most of which tie in with books he knows. The "Living Books" software, by Broderbund (800-567-2610),


Weston Woods videos adapt award-winning children's books into video format. Shown here, "Where the Wild Things Are."

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are wonderful, with many titles to choose from. One caution in using computers: children with autism can become self-stimulatory on one aspect or another in the software. My son loves to watch the credits of most software, over and over. I have to use the credits as a reward for actually playing with the software appropriately.

In terms of satisfaction and encouraging expansion of horizons, nothing can quite compare to a book. Books were the absolutely irreplaceable item in my son's life. Reading to him was the very first thing we were able to do together. It was the first interaction we had ever had that wasn't about a basic need. Since then, my son has enjoyed many books and I am certain he learned language from them. His fondness for books is most certainly due to the predictability of a book, once he heard it a few times. But I'd like to think it is also due to the security he derived from the contact of leaning against me, and the pleasure of hearing my voice. Even now, at age 10, he brings books to me to read to him, even though he himself can read.

Any book goes over better with my son if there is a video or a computer game that goes with it. Check out the Weston Woods video series (203-226-3355), a division of Scholastic, Inc. They animate many of the classic Caldecott-award kind of books. Most are available in public libraries. When my son can go from reading a book, to seeing it on TV, to playing an interactive version on CD, he's a really happy guy. It makes the stories come alive.

DON'T DESPAIR OVER THE DIFFICULTY OF ENTERTAINING YOUR CHILD.

Toys that worked for my child will not work for every child with autism. Developmental rules don't apply here, many children with autism's love predictability and repetition, as well as the need for sensory input and approaches that use all forms of communication (audio, video, and text). You can choose toys with reasonable success by keeping in mind: The most important thing is to try not to despair if toys you've picked don't seem to interest him or her right away. Try them again at a later date, or understand what this dislike implies about your child's tastes. It's crucial to observe your child in his likes and his dislikes because the knowledge you will gain will be highly useful when trying to teach him new things. Likes and dislikes are strong motivators, and make handy rewards.

Buying a toy for child with autism can be a chore and a heartbreaking endeavor. But with a little observation of your child and a willingness to fail and try again, parents can find the right toys and expand their child's abilities with them.

As long as we accept our children for the unusual people they really are, and try to appreciate their uniqueness, it is possible to play with them and get them to interact with us meaningfully and pleasurably. ■

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LEGISLATIVE UPDATE

FAMILY OPPORTUNITY ACT: Hot Issue on Capitol Hill

by Kathleen McGinley, PhD

The Family Opportunity Act of 2000 (FOA) was introduced in the Senate by Sens. Charles Grassley (R-Iowa) and Ted Kennedy (D-Mass.) on March 22. Since then it has grabbed the interest and support of both advocates and members of Congress. As this article goes to press, the Senate bill, S. 2274, has 75 co-sponsors.

The House bill, H.R. 4825, which was introduced by Reps. Pete Sessions (R-Texas), Henry Waxman (D-Calif.), Fred Upton (R-Mich.), and Thomas Barrett (D-Wis.) on July 12, has 97 co-sponsors from both sides of the aisle.

On the morning of July 12, a well-attended hearing on the Senate bill was held before the Senate Budget Committee. The FOA sponsors wanted a hearing before the Finance Committee because it has jurisdiction over the bill. However, Sen. Grassley's request for a hearing in that committee was denied. Therefore, Grassley scheduled a hearing in the Budget Committee where he had successfully included $150 million (over five years) in the FY 2001 Budget Resolution as a "down payment" to fund the Family Opportunity Act.

Witnesses at the hearing included the parents of three children with disabilities: Sen. Kennedy and Rep. Sessions; the Governor of Arkansas; the Director of the Health, Education, and Human Services Division of the General Accounting Office; and a representative of a children's hospital.

The Arc and other major children's, family, education, and child health organizations strongly support the FOA. It is seen as a pragmatic and responsible policy effort that, if enacted, will help to ensure that less children "fall through the cracks" and more children with disabilities have access to a broad range of needed healthcare services and supports.

The most critical provisions of the bill would allow states (state option) to offer Medicaid coverage to children with severe disabilities — physical or mental—who live in middle-income families. Currently, these children are ineligible for Medicaid because their families make too much money. In addition, these children often are uninsured or underinsured because health insurance is not available through an employer; is too expensive; or offers a very limited benefits package. Giving parents the option of buying into Medicaid and paying on a sliding-scale basis would provide children with disabilities in these families with access to the full range of Medicaid services, including those provided through the Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) program. This provision, along with the demonstration program that would allow states to cover children with "potentially severe disabilities" promises improved health, the prevention of future disabilities, and a better chance for these children to live full and healthy lives with their families in their home communities. A third section of the bill would set up family-to-family health information centers.

There are a few important differences between the House and Senate bills. One is that the House bill would probably require that parents contribute less in the Medicaid "buy-in." Another difference is that the demonstration program in the House bill would only apply to children ages 0-5 and not up to age 21. This would, in turn, lower the overall cost of the demonstration and potentially could make the bill easier to pass.

How advocates can help

Time is very short. This Congress ends on October 6 and there are many items on the congressional agenda. The FOA should be one of their priorities.

You can urge your Representatives to co-sponsor the FOA and ask Chairman Bliley (R-Va.) for quick action in the House Commerce Committee. Also urge them to ask House republican and democratic leaders for floor action as soon as possible.

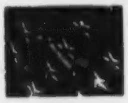
The same holds for your Senators: urge them to co-sponsor the FOA and to ask Senate republican and democratic leaders for floor action as soon as possible.

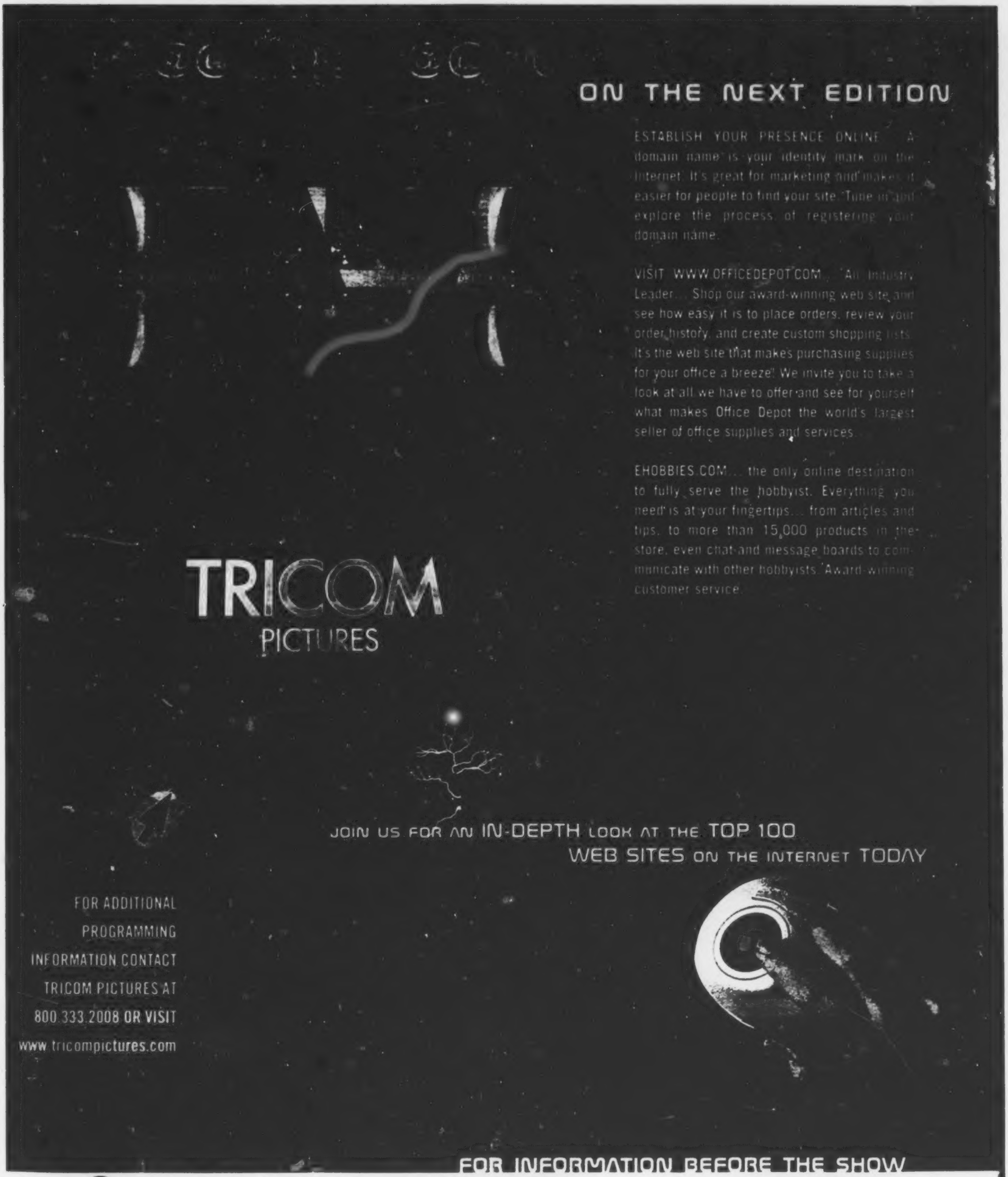
For a list of current co-sponsors and to contact your members of Congress, see The Arc's Web site (http://www.thearc.org) and click on the Action Center for information as well as updates on the status of the FOA.

Parents can check with the Arc and future of issues of EP to find out if the legislation has passed and how to take advantage of it, or how to continue to advocate for its passage.

Whatever the outcome, this important piece of legislation must not be forgotten.

Kathleen McGinley, PhD, is the Director of Health and Housing Policy for The Arc of the United States. Readers can contact Dr. McGinley at telephone: (202) 785-3388; or E-mail: McGinley@thearc.org.





ON THE NEXT EDITION

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Phoenix & Tucson

Each election year, EP invites the Presidential candidates to discuss their positions on issues that affect people with disabilities and their families. The platforms of Vice President Al Gore and Texas Governor George W. Bush are presented below. The candidates' statements appear exactly as they were received from each party's offices.—The Editors

The Presidential Candidates speak out

George W. Bush

I believe that all Americans should have the opportunity to learn and develop their skills, engage in productive work, choose where to live, and participate in community life. Too often, however, people with disabilities are trapped in bureaucracies of dependence and are denied the tools and access necessary for success. The result has been that too many Americans are shut out from the American dream. I know that parents of children with exceptional needs have exceptional demands on their time, energy, and their resources. And unfortunately, citizens with disabilities have met more obstacles than just their physical or mental challenges while trying to live in their community. We must do everything that we can to ensure that more Americans with disabilities can live independently, hold jobs, and take part in the life of their communities.

Today there are more than 7.5 million disabled Americans receiving benefits under federal disability programs. However, less than 1 percent of those receiving disability benefits enter the workforce. That is why I support federal legislation providing disabled Americans with the option to choose their own support services, including vocational education programs and rehabilitation services. In addition, I have proposed the New Freedom Initiative, an $880 million five-year plan that will help Americans with disabilities, young or old, have every chance to pursue the American dream.

The $880 million New Freedom Initiative encourages businesses to hire Americans with disabilities by taking three important steps. First, I will triple federal funding in assistive technology and dramatically improve access to it. Second, I will provide $20 million to help disabled Americans work from home and make the providing of a home office by a company a tax-free fringe benefit. Third, I am committed to signing an Executive Order to allow Americans with disabilities to maintain their health benefits when they return to work.

The federal government must fulfill its responsibilities to all of America's citizens. I believe that no child should be left behind, including those with disabilities. That is why I will work with Congress to increase funding for special education with the goal of meeting the federal obligation under the Individuals with Disabilities Education Act.

Originally passed by Congress in 1975, the Individuals with Disabilities Education Act, or IDEA, ensures that children with disabilities would have a free public education that would meet their unique needs. However, the federal government has

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not been providing sufficient funding for IDEA. Because the federal government has failed to provide its fair share of the responsibility, state and local governments have been needlessly strapped, and unfortunately care for our nation's disabled citizens has suffered as a consequence. This must stop. We live in an era of unmatched economic prosperity. But I have argued over these past many months, that our prosperity must have a higher purpose. The purpose of prosperity is to make sure the American dream touches every willing heart. The purpose of prosperity is to leave no one out—to leave no one behind.

In addition, I believe that it is equally important to emphasize preventive efforts to identify children with special needs. Early detection of needs will greatly benefit children by giving students the necessary help early. I will focus funding on students in the elementary grades, where math and reading difficulties can be corrected before children are diagnosed as needing special education services. States who choose to draw from the fund will be required to initiate: a reading diagnostic test for students in K-2 to determine where students need help, a research-based curriculum, training for K-2 teachers in reading preparation, and intervention for students who are not reading at grade level in K-2.

On June 22, 1999, the Supreme Court ruled in Olmstead v. L.C. that the Americans with Disabilities Act (ADA) requires that people with mental disabilities be placed in a community setting whenever possible. Unfortunately, Olmstead has yet to be implemented. If I am elected I vow to sign an Executive Order supporting the swift implementation of the Olmstead decision. I will support the most integrated community-based settings for individuals with disabilities possible and call for the identification and removal of barriers to community placement. I believe that community-based care is critically important to promoting maximum independence and to integrating individuals with disabilities into community life.

Access to health care is also important and should be a priority. I have supported legislation that extends Medicare coverage for Social Security Disability Income (SSDI) beneficiaries so they can return to work without the fear of losing health benefits and expanded Medicaid eligibility categories for SSI recipients. Under this legislation I supported, SSDI beneficiaries can continue to receive benefits even after their income, resources, or medical condition improves. As President, I will aggressively implement these improvements for persons with disabilities.

For those families who choose to care for their loved ones at home, we need to support that decision in every way possible. Family caregivers have been called the "invisible health care sector." Not only do they supply billions of dollars in healthcare value; they give help that no one can put a price on—the compassion and comfort of family love. They deserve our support.

I am proud of our accomplishments on behalf of disabled citizens in Texas. As Governor, I worked with the Legislature to increase funding for community-based services by more than $1.7 billion, a 72 percent increase. I also promoted and signed legislation that created the Children's Health insurance Program providing access to health care for every child up to 200 per cent of the poverty level, including children with disabilities. I also appointed a number of disabled Texans to various positions and boards in Texas because they were the best men and women for the jobs.

I have traveled all over this great country and I have met a lot of wonderful people. But I know that people have suffered, from what I refer to as the "soft bigotry of low expectations." Unfortunately, this bigotry is evident in the hearts and minds, and on the faces of so many people. So our society and our government must make every effort to enable people with disabilities to lead independent and productive lives. It is not only what is right, but it is our duty to ensure that every American is empowered with the tools and resources necessary to, with hard work and dedication, live the American dream. ■

[redacted]

Although challenges are sometimes exacerbated by limited educational opportunities, inadequate facilities, and unfair discrimination, we have made progress in breaking down these obstacles, both legislatively and socially. Throughout Al Gore's time in public office, he has supported legislation that helps eliminate the barriers that people with disabilities confront. Gore supported and still supports the Americans with Disabilities Act (ADA), and as Vice President, has worked hard to achieve the ADA's core goals—equality of opportunity, full participation, independent living, and economic self-sufficiency. America is now a dramatically different—and better—country because of the ADA. But there is still a lot of work to be done. As President, Al Gore will further these accomplishments, working to expand educational opportunities, improve access to quality healthcare, expand employment opportunities, and eliminate discrimination for all people with disabilities.

Al Gore

EXPANDING EDUCATIONAL OPPORTUNITIES

Every child should have equal access to education—including children with special needs. Al Gore has long supported the rights of children with disabilities under the Individuals with Disabilities Education Act (IDEA). As President, he will continue enforcement efforts and provide new resources to help communities educate children with special needs. Specifically, Al Gore's plan includes:

- The Largest Ever Increase In Special Education Funding and Expanded Funding Pools. In his first budget, Al Gore will propose the largest increase ever enacted under the Individual with Disabilities Education Act (IDEA) and is committed to the goal of the Federal government contributing 40 percent of IDEA. This investment will strengthen the federal commitment to help states and school districts educate children with disabilities, while supporting other initiatives to help all students get the high-quality education they need and deserve. He also supports the establishment or expansion of state-managed funding pools to help cover the costs of educating the relatively few children with disabilities who require high-cost services to attend local public schools.
- Increase Funding For Parent Training and Information Centers. As part of the effort to make special education more affordable and to make education in the least restrictive environment a reality for youth

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with disabilities, Al Gore will increase funding for Parent Training and Information Centers to $50 million—double the Administration's current budget request.

IMPROVING ACCESS TO QUALITY HEALTH CARE, INCLUDING MENTAL HEALTH SERVICES

Throughout his time as Vice President, Al Gore has been committed to improving America's health care system. Gore knows how expensive health coverage can be, especially for families with a child who has a disability. As President, he will continue to fight for a more accessible and fair healthcare system, one that will include all America's children. He will begin by:

- Providing a long overdue prescription drug benefit that is available and affordable for all medicare beneficiaries. Al Gore has proposed a prescription drug benefit that covers half of all prescriptions from the first trip to the pharmacy up to $5,000 per year in prescription drug costs. It also contains catastrophic protections to ensure that no beneficiary has to pay more than $4,000 per year out of pocket. Finally, it covers cost-sharing for low-income beneficiaries. Al Gore does not support the Republican proposals administered by the private insurance industry, which will discriminate against sick beneficiaries with high health care needs. Also, Al Gore does not support a low-income only benefit that would leave behind a person with a disability who earns more than $20,000.
- Enacting a $3,000 long-term care tax credit For Caregivers. Al Gore believes that we must make long-term care more affordable and that we must start by giving Americans with long-term care needs or their caregivers a $3,000 tax credit to defray the cost of long-term care costs.
- Passing a strong, enforceable Patient's Bill of Rights. Al Gore supports a strong enforceable patient's bill of rights that ensures all patients in all health plans adequate protections, such as access to specialists, access to emergency room care when and where the need arises, and access to appeals process for patients and doctors who disagree with decisions made by health plans.
- Assuring full mental health parity for children. Approximately one in five children experience symptoms of a mental health disorder during the course of a year. However, 70 percent of those who need treatment do not receive mental health services. Left untreated, a child's mental illness can lead to poor performance in school, substance abuse, delinquent behavior, violence and suicide—one of the leading causes of death for young people. Al Gore's Administration will ensure that every child has access to full mental health coverage. It will require insurers to offer full mental health parity for children, including equitable cost-sharing and treatment for all services. And as coverage to every child in America is expanded, through the Children's Health Insurance Program (CHIP), disparities in treatment for physical and mental illness for all children will be eliminated.
- Assuring no parent is forced to choose between custody and needed mental health services. Studies by the Bazelon Center show that some parents have given up their children to child welfare services to make sure they receive mental health services they need. In addition to assuring full mental health parity for children, the Gore Administration will examine other barriers that prevent children from receiving mental health services and work to assure that no parent has to give up their child to get mental health treatment.
- Investing in community mental health services while holding programs accountable. As Vice President, Al Gore fought for historic increases in community mental health care. As President, Al Gore will continue to invest in record increases to expand the availability of community mental health services. These programs will be required to use quality, evidence-based treatment.

EXPANDING EMPLOYMENT OPPORTUNITIES FOR PEOPLE WITH DISABILITIES

Approximately 30 million working-age adults with disabilities live in the United States. About 75 percent of people with significant disabilities are unemployed or underemployed. Studies show that 80 percent of people with disabilities would work if they were able to do so without losing their healthcare. To address these issues, Al Gore proposed to launch a Disability-to-Work Initiative, involving the private and public sectors in a major national effort to increase employment of people with disabilities. The Disability-to-Work Initiative will:

- Challenge the private sector to increase hiring of people with disabilities. Al Gore will launch a partnership including businesses and non-profits to help move people with disabilities into work, provide them with the skills and assistive technology they need to enter into the workforce, and share best practices.
- Prepare youth with disabilities for work. Al Gore will work with non-profit technology resource centers and businesses to provide students the assistive technology they need to be prepared for the workforce. Gore will challenge businesses to provide meaningful job opportunities for youth with disabilities, so that when they graduate from high school they can enter the workforce or continue on to higher education. Gore also will work to ensure that school-to-work transition services target youth with disabilities.
- Ensure that the federal government does its fair share in moving people with disabilities into work. Al Gore proposed to double the federal government's hiring of people with disabilities and double the number of youth with disabilities in government internships. He also will work to ensure that the federal government's technology is accessible to people with disabilities and encourage the private sector to develop accessible

technology.

- Enact a $1,000 tax credit for work-related expenses. Al Gore believes that we must make it easier for people with disabilities to succeed in the workplace—and participate in and contribute to the American dream. He supports a tax credit to help individuals defray work-related costs such as transportation and personal assistance.
- Double the administration's proposed investment in accessible technology. Technology is a crucial component in enabling people with disabilities to work. Al Gore proposes to double the Administration's investment in the development of assistive and communications technologies to help people with disabilities work. Funds will support new and expanded state loan programs to make assistive technology more affordable for Americans with disabilities. Though Congress cut funding to less than $10 million, Al Gore will fight to increase such investments—doubling the Administration's current budget request of $35 million per year to $70 million per year in his budget.

ELIMINATING DISCRIMINATION THROUGH TOUGH ENFORCEMENT OF CIVIL RIGHTS LAWS

Our first step towards improved civil rights is enforcing the laws we already have. Al Gore is committed to full implementation and enforcement of the laws protecting the rights of individuals with disabilities. He proposes to:

- Toughen enforcement of ADA, IDEA and Fair Housing Act. His Administration will aggressively enforce civil rights laws protecting people with disabilities. One of his top priorities will be to increase funding for all government agencies that enforce these civil rights laws. In particular, as President, he proposes to increase the funding for the US Department of Health and Human Services' Office of Civil Rights by $50 million over ten years.
- Strengthen the Hate Crimes Law to include disability. Al Gore will continue to fight for federal hate crimes legislation to protect victims who are targeted simply because of who they are. Al Gore pledges to work with the Congress to pass the Hate Crimes Prevention Act, which will expand the definition of hate crimes to include disability and allow for the prosecution of these crimes under federal law.

ENABLING PEOPLE WITH DISABILITIES TO LIVE IN THEIR OWN COMMUNITIES

Al Gore believes that no individual should have to live in an institution such as a nursing home or hospital if he or she can live in the community with the right support. He supported the recent Supreme Court (Olmstead v. L.C.) ruling that unjustified isolation of institutionalized people violated the Americans with Disabilities Act (ADA) requirement to provide services in an integrated setting. Al Gore's plan will:

- Ensure that people with disabilities live in the most appropriate integrated settings. As President, he will work with states, people with disabilities and senior citizen advocates to develop comprehensive plans for enabling persons with disabilities to live in the most integrated setting appropriate to their needs. He proposes funds for a variety of activities that will ensure individuals have a choice in where they live, whether in their own home or the community.
- Establish the Fund for Independence, which will maximize resources to develop home and community-based services. As President, Al Gore will establish a public-private partnership to help increase the availability and quality of personal assistance and support for people with disabilities who wish to live at home and in their own communities, and those who wish to join the work force. People with disabilities may need a personal assistant at home, work or school; accessible transportation to work and school; and other supports to live independently. The Fund will include representatives from federal and state governments, foundations, unions and communities that support innovative community efforts to provide appropriate services, and will work to identify best practices for providing personal assistance services and supports.
- Enable states to expand home- and community-based care. Medicaid has historically had an institutional bias by reimbursing for nursing home care at a higher level than care provided at home and in the community. Al Gore has proposed allowing states to expand reimbursement by Medicaid for home- and community-based care to the same income levels as for nursing homes, without receiving a federal waiver.
- Increase funding for Independent Living Centers to $75 million. Independent Living Centers (ILCs) are often the single source for independent living resources for people with disabilities. ILCs offer personal assistance services and supports—such as personal attendants and transportation—necessary for people to live independently. As President, Al Gore will continue to fight for additional funding to enable the ILCs to carry out their critical mission and help people live independently. Al Gore proposes that his first budget will include $75 million per year for ILCs (the current Administration budget requests $40 million per year).
- Increase collaboration around housing issues. Al Gore will fight to address the housing crisis facing individuals with disabilities and their families. He will ensure that HUD collaborates with the disability community, public housing authorities and other interested parties to address housing issues for people with disabilities. He will work to expand home ownership programs for people with disabilities and their families.

These initiatives are the first steps towards equal opportunity for all Americans. Throughout Al Gore's time in public service and throughout his life, he has been committed to helping people with disabilities and their families fight discrimination. There is still a lot of work to be done. ■

WHAT IF THEY GAVE AN ELECTION ON NOVEMBER 7, 2000 AND EVERYBODY CAME?

by Gail Chasey Beam

What if every single family member of the 12.6 million children in this country with special healthcare needs voted? What if each of us contacted our own state legislators, our U.S. Senators and Representatives to tell them our stories? What if we educated every single new candidate for public office about our children's needs and made certain that they understand exactly what they, as policy makers and leaders, must do for our children so that they have the healthcare they need? The possibilities are staggering. What can we do to make these possibilities reality? We can make our presence known and our voices heard. Each of us can educate our candidates. Here is how.

How to advocate for our children through the election process

WHO? Each and every one of us who has or cares about a child with special healthcare needs.

WHAT? Register to vote. Work for candidates. Talk to friends and neighbors. And vote!

WHEN? Especially in an election year, but any time that candidates are lining up to run and when Congress or state legislatures are in session or at home visiting constituents.

WHERE? At candidate forums, neighborhood meetings, League of Women Voters' gatherings, town halls, your legislators' home or capitol offices, at the state legislature, and in the halls of Congress. Call the League of Women Voters to find out about forums.

WHY? Kids cannot vote. Kids do not lobby. They need their families and friends to speak up for them. It works! Just ask Bob Craig from West Virginia, whose Children's Health Insurance Program/CHIP will now include dental, vision, and hearing services because of testimony he gave at a state legislative hearing. Just ask Julie Beckett, who refused to leave her daughter in a hospital many years ago, and helped establish the Medicaid Waiver programs through her political activism. Just ask Dawn Wardyga, whose U.S. Senator became an advocate for her son and a personal family friend.

HOW?

1. Contact your League of Women Voters or the Democratic or Republican county office for the following information:

The names of your representatives in your state legislature and in Congress;

The names of those running for reelection and their challengers.

2. Then,

Get to know these people.

Tell them your stories.

Tell them what they need to do when they are elected.

Offer to work in the campaigns of those who listen and promise to help.

Contribute money when you can. (Even small donations of $10 to $25 are gratefully accepted. When Ann Richards ran for Governor of Texas, she raised 8 million dollars from people who gave $25.00 each.)

When your candidates are elected, stay in touch. Keep them informed. Let them know they can count on you for good and honest information.

If your call to an elected official or a candidate is not returned, call again. This is expected.

3. You can also:

Link up with other health and child advocate groups who work on state and national issues. Add your voice to theirs!

Attend legislative committee hearings when the legislature is in session.

Contact your state and Congressional representatives via e-mail about important issues. Your stories and personal touch will make a difference in the lives of many children.

If we can help, contact us. We are Family Voices, and we want to be sure that all of our voices are heard! Our Web site is http://www.familyvoices.org. Or contact the Family Voices office toll free, (888) 835-5669. ■

Adapted from Family Voices Newsletter, July-August, 2000. Family Voices is a national grassroots network of families and friends speaking on behalf of children with special health care needs. Family Voices Newsletter is made possible by grants from The Robert Wood Johnson Foundation and the US Maternal Child Health Bureau.

Gail Chasey Beam is the Director of Network Development for Family Voices and State Representative in the New Mexico Legislature.

Web sites

Getting Out the Disability Vote:
http://nod.org/vote2000/vote2000.html

Register to Vote Online at:
http://www.beavoter.org

For Your State's Election Resources:
http://www.iupui.edu/~epackard/eleclink.html

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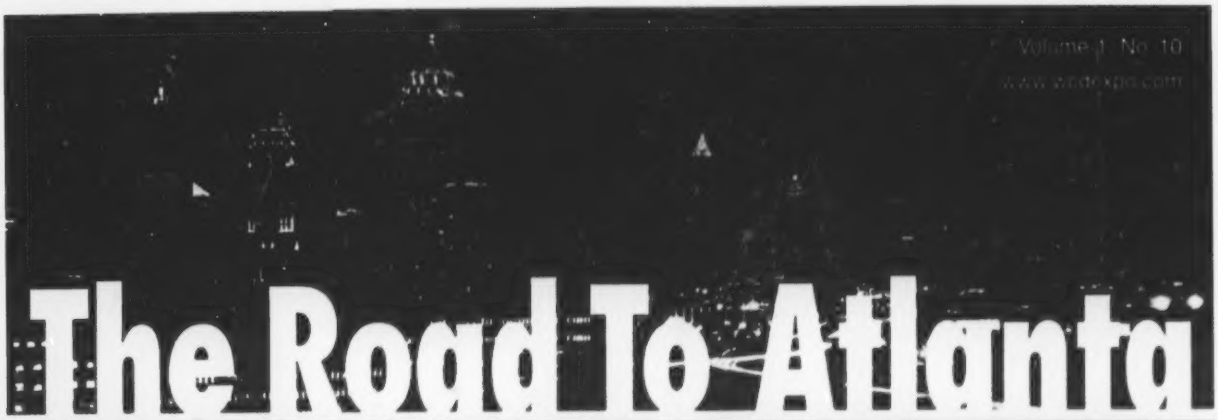

Volume 1 No 10
www.wcdexpo.com

The Road To Atlanta

NOVEMBER 10-12, 2000 • WORLD CONGRESS & EXPOSITION ON DISABILITIES

A Multitude of Exhibits Will Await WCD Attendees

The 8-10,000 expected attendees at the first World Congress & Exposition on Disabilities (WCD), taking place November 10-12 in Atlanta, will be able to examine a broad array of products and services from approximately 200 exhibitors. Because the WCD is combining all elements of the disabilities field (people with disabilities and their family caregivers, as well as physicians and others involved in the care and development of people with disabilities), exhibits will include everything from disability-specific equipment to general educational materials and information.

The displays will fill the accessible Georgia International Convention Center with a variety of specialized devices, along with examples of toys and clothing, books and magazines, and pharmaceutical and nutritional materials. In addition, there will be informational exhibits presented by hospitals and clinics; schools and camps; travel, financial management and vocational services; and at least 30 organizations with knowledge and interest in a variety of healthcare and disability issues.

One precedent-setting aspect of the WCD will be the convergence under one roof of professionals and consumers with shared involvement in the community of people with disabilities. More than 80 educational sessions in four tracks of interest will be taking place, each aimed at a specific audience, but all open to any conference registrant. Those tracks include medical, education, families/ caregivers/ people with disabilities and adapted physical activity directors and teachers.

Two major organizations are granting accreditation. Emory University School of Medicine is offering Continuing Medical Education (CME) credits for the physician and healthcare track and the Council for Exceptional Children is granting Continuing Education Units (CEU) for the education track of seminars.

In addition to the exhibits, the show floor will feature a Sports Activity Center with demonstrations on wheelchair basketball, rugby, tennis, fencing, track and field. A full size basketball court will be the center of the sports schedule. Top athletes in these respective sports along with appearances by the Rolling Hawks wheelchair basketball team and the Rolling Thunder wheelchair rugby team will demonstrate how people with disabilities can participate in sporting activities. There also will be audience participation. The Sports Activity Center is organized by the U.S. Disabled Athletes Fund in Atlanta and Special Olympics, and sponsored by Sports 'N Spokes magazine and Home Depot.

Other special areas include pavilions for schools and camps, non-profit organizations, book publishers, assistive technology and career fair.

For more information on how to exhibit or to attend the WCD, call toll free 877-923-3976 or go to the website at www.wcdexpo.com.

WORLD CONGRESS & EXPOSITION ON DISABILITIES
WCD

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Sports & Recreation Activity Center: Features top athletes with disabilities in wheelchair basketball, tennis, rugby, track & field and soccer.

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Career Fair: Human resources managers will meet people with disabilities, allied healthcare professionals and educators.

WCD CONFERENCES ARE:

For Families, Direct Support Professionals and People with Disabilities: Experienced parents and professionals share strategies and techniques for planning and problem-solving in the home, the family, the community and the world at large.

For Physicians, Physical Therapists, Occupational Therapists, and Other Healthcare Professionals: Seminars presented by internationally renowned experts. CME credits through the Emory University School of Medicine; CEU credits through other approved accreditation providers.

For Educators: For all those involved in the educational development of people with disabilities or special healthcare needs. CEU credits through the Council for Exceptional Children.

The CME-accredited program has been planned and implemented in accordance with the Essential Areas and Policies of the Accreditation Council for Continuing Medical Education (ACCME) through the joint sponsorship of the Emory University School of Medicine and the EP Foundation for Education. The Emory University School of Medicine is accredited by the Accreditation Council for Continuing Medical Education to provide continuing medical education for physicians.

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Answers to Parent Questions About

ADD/ADHD

by Children and Adults with Attention Deficit-Hyperactivity Disorder CHADD)

In 1987, few people knew about, much less understood, attention deficit disorder (also known as attention deficit-hyperactivity disorder or ADD/ADHD). That was the year that a group of parents in Florida with children with ADD/ADHD started a support group to help each other, their children and their families understand and cope with their frustration and sense of isolation.

Thirteen years later, that support group has grown dramatically to become the leading non-profit national organization for children and adults with AD/HD: CHADD—Children and Adults with Attention-Deficit/Hyperactivity Disorder. While the organization—now headquartered in Landover, Maryland (there is also a CHADD-Canada)—has a small national staff, it continues to be run by volunteers. And it has never lost the passion and commitment that launched what has become a major print, electronic and one-on-one source of information, research studies, and support for people with AD/HD.

One of the key purposes of CHADD is to provide advice and counsel for parents of children with disabilities. Following are frequently asked questions for which CHADD has tried to provide helpful and practical answers for parents in communities around the country. For more information, call CHADD at (301) 306-7070, e-mail at national @Chadd.org, or visit their Web site at http://www.Chadd.org.

CHADD Frequently asked Questions on ADD/ADHD

1. Does my child have attention deficit/ hyperactivity disorder?

All children may be overly active at times, their attention spans may be short, and they may act without thinking. However, if your child seems more active than others the same age; if your child is notoriously forgetful, disorganized, and always losing things; if the teachers complain that your child cannot stay seated or quiet, blurts out answers instead of waiting to be called on, pays more attention to the traffic in the hall than to the teachers, behaves aggressively, or struggles academically, then you may want to have your child evaluated for ADD/ADHD.

Determining if a child has ADD/ADHD is a multifaceted process. Many biological and psychological problems can contribute to symptoms similar to those exhibited by children with ADD/ADHD. For example, anxiety, depression, and certain types of learning disabilities may cause similar symptoms. A comprehensive evaluation is necessary to establish a diagnosis, rule out other causes, and determine the presence or absence of other influential conditions. Such an evaluation should include a clinical assessment of the child's academic, social, and emotional functioning, and developmental abilities. Additional tests may include intelligence testing, measures of attention span, and parent and teacher rating scales. A medical

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exam by a physician is also important.

Diagnosing ADD/ADHD in an adult requires an examination of childhood, academic, and behavioral history. The problems need to be rooted in childhood but persist into adulthood. ADD/ADHD symptoms often arise in early childhood. ADD/ADHD is diagnosed using the criteria in the *Diagnostic and Statistical Manual, 4th Edition (DSM-IV)*. To meet the diagnostic criteria for ADD/ADHD, symptoms must be evident for at least six months, with onset before the child reaches age 7.

Diagnostic criteria are as follows:

Inattention

A child who is inattentive:

- often fails to give close attention to details or makes careless mistakes in schoolwork, work, or other activities
- often has difficulty sustaining attention in tasks or play activities
- often does not seem to listen when spoken to directly
- often does not follow through on instructions and fails to finish schoolwork, chores, or duties in the workplace (not due to "bad" behavior or failure to understand instructions)
- often has difficulty organizing tasks and activities
- often avoids, dislikes, or is reluctant to engage in tasks that require sustained mental effort, such as schoolwork or homework
- often loses things necessary for tasks or activities (for example, toys, school assignments, pencils, books, or tools)
- is often easily distracted by extraneous stimuli
- is often forgetful when undertaking daily activities

Hyperactivity-Impulsivity

A child who is hyperactive or impulsive:

- often fidgets with hands or feet, or squirms in his or her seat
- often leaves his or her seat in classroom or in other situations in which remaining seated is expected
- often excessively runs about or climbs in situations in which it is inappropriate to do so (in adolescents or adults, this may be limited to subjective feelings of restlessness)
- often has difficulty quietly playing or engaging in leisure activities
- is often "on the go" or often acts as if "driven by a motor"
- often talks excessively
- often blurts out answers before questions have been completed
- often has difficulty waiting his or her turn
- often interrupts or intrudes on others

2. Can my child have ADD/ADHD and not be hyperactive?

Yes. The American Psychiatric Association's *DSM-IV* identifies three types of ADD/ADHD: predominantly hyperactive-impulsive type, predominantly inattentive type, and combined type.

Determining if a child has ADD/ADHD is a multifaceted process. Many biological and psychological problems can contribute to symptoms similar to those exhibited by children with ADD/ADHD.

3. How is ADD/ADHD treated?

Most experts recommend a multimodal treatment approach for ADD/ADHD, consisting of a mix of medical, educational, behavioral, and psychological interventions. Interventions may include educational modifications and accommodations, behavior modification, parent training, counseling, and medication.

Psychostimulants (such as methylphenidate, dextroamphetamine, and pemoline) are the most widely used medication for the management of ADD/ADHD-related symptoms. Between 70 and 80 percent of children with ADD/ADHD respond positively to psychostimulant medications. Other medications include some antidepressants and antihypertensives. These medications increase attention and decrease impulsivity, hyperactivity, and aggression.

Behavior management is an important intervention with children who have ADD/ADHD. The most important technique is positive reinforcement, in which the child is rewarded for desired behavior.

Classroom success may require a range of interventions. Most children with ADD/ADHD can be taught in the regular classroom setting with either minor adjustments, the addition of support personnel, and/or "pull-out" programs that provide special services outside of the classroom. The most severely affected children may require self-contained classrooms.

Adults with ADD/ADHD can benefit from learning to structure their environment. Medications effective in childhood ADD/ADHD also appear useful with adults who have ADD/ADHD. Vocational counseling is often an important intervention.

Short-term psychotherapy can help someone with ADD/ADHD identify how his or her disability might be associated with a history of poor performance and difficulties with personal relationships. Extended psychotherapy can help address any mood swings, stabilize relationships, and alleviate guilt and discouragement.

4. Can the school make my child take Ritalin?

The decision to place a child on psychostimulant medications such as Ritalin can only be made by a physician and with the parental consent. Ritalin treatment therefore cannot be mandated by school personnel. Teachers, however, might suggest it because they have seen it help other students with ADD/ADHD.

Adults with ADD/ADHD can benefit from learning to structure their environment. Medications effective in childhood ADD/ADHD also appear useful with adults who have ADD/ADHD.

A rumor has been circulating that schools can put children on Ritalin without parents' knowledge. This is totally unfounded, since Ritalin is a highly controlled substance. Federal law prohibits doctors and pharmacies from providing Ritalin to schools; prescriptions can only be written and filled for individuals following strict guidelines.

5. Are psychostimulants such as Ritalin safe?

Hundreds of studies on thousands of children have been conducted regarding the effects of psychostimulant medications, making them among the most studied medications in pharmacological history. Relatively few long-term side effects have been identified. Most problems related to these medications are mild and short-term. The most common side effects are reduction in appetite and difficulty sleeping. Infrequently, children experience "stimulant rebound"—a negative mood or an increase in activity as the medication is wearing off. This tends to occur in younger children, and is more frequent with short-acting medication. These side effects are usually managed by changing the dose and the scheduling for short-acting medications, or by changing to a prolonged-release formulation.

There may be an initial, slight effect on height and weight gain, but studies suggest that ultimate height and weight are rarely affected. However, for any child who seems to be lagging behind his or her peers, height and weight should be closely monitored. Some studies suggest that children with ADD/ADHD reach puberty later than their peers.

A relatively uncommon side effect of psychostimulant medications may be the unmasking of latent "tics"—the medical term for involuntary, excessive motor movements (such as eye-blinking or shrugging), or vocalizations (such as throat clearing or sniffing). Psychostimulant medications can facilitate the emergence of a tic disorder in susceptible individuals. Often, but not always, the tic will disappear when the medication is stopped.

Many individuals who have ADD/ADHD tics, will experience tics in their mid-teens as a time-limited phenomenon related to their disorder. The medications may bring them out earlier or make them more prominent than they would be without medication. These tics will eventually go away in the latter part of the teenage years, even while the individual is still on medication.

6. Are there any drug-free treatments for ADD/ADHD?

Most experts recommend a multimodal treatment approach for ADD/ADHD, consisting of a mix of interventions. Drug-free interventions that have been shown to be effective include educational interventions, behavior modification, parent training, and counseling in anger management.

In an effort to seek help for ADD/ADHD, some people may turn to treatments that others claim to work but that have not been shown to be effective using rigorous scientific standards. To make sure that treatments are safe and effective, avoid controversial treatments and ask how suggested treatments have been evaluated.

7. Does my child qualify for special education?

IDEA provides special education for children who meet the eligibility criteria for one of a number of categories. If the child meets the criteria listed under one category and the disabling condition adversely affects educational performance, requiring special education, he or she may be eligible to receive services under this law.

In its regulations implementing IDEA, the US Department of Education includes ADD/ADHD as a condition that may qualify a child for special education services under the "Other Health Impaired" category. A child may be eligible under this category if the disorder limits alertness to academic tasks, adversely affecting educational performance to the extent that special intervention is necessary.

8. What is a 504 plan?

Section 504 is a civil rights statute that prohibits schools from discriminating against children with disabilities and requires that

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they provide "reasonable accommodations." Under some circumstances, these reasonable accommodations may include the provision of services (for example, see question 10 below).

Eligibility for Section 504 is based on the existence of an identified physical or mental condition that substantially limits a major life activity. Since learning is considered a major life activity, children diagnosed with ADD/ADHD are entitled to the protections of Section 504 if the disability substantially limits their ability to learn. Children who are not eligible for special education may still be guaranteed access to related services if they meet the Section 504 eligibility criteria

9. How does ADD/ADHD affect schoolwork?

Students with ADD/ADHD have a greater likelihood of being kept back, dropping out of school, academic underachievement, and social and emotional adjustment difficulties, unless they receive adequate and appropriate treatment. This is probably because ADD/ADHD makes children vulnerable to failure in the two most important arenas for developmental mastery—school performance and peer relations.

Children with ADD/ADHD are not unable to learn, but they do have difficulty performing in school due to poor organization, impulsivity/hyperactivity, inattention, and distractibility. However, some children with ADD/ADHD also have learning disabilities, further complicating identification and treatment.

Children with ADD/ADHD are guaranteed a free and appropriate education to meet their needs under two federal laws: the Individuals with Disabilities Education Act, Part B (IDEA), and Section 504 of the Rehabilitation Act of 1973.

ADD/ADHD frequently coexists with other learning, behavioral, emotional, and developmental problems. These include learning disabilities—particularly reading, writing, spelling, and math—speech and language disorders, conduct disorder, oppositional defiant disorder, mood disorders, and anxiety disorders. ADD/ADHD also affects memory—especially working memory—and organization.

Untreated ADD/ADHD can lead to poor self-esteem and poor social adjustment. Children with ADD/ADHD commonly experience interpersonal difficulties and peer rejection, and have been shown to elicit more negative feedback from teachers.

ADD/ADHD occurs across all levels of intelligence, yet even bright or gifted children with ADD/ADHD may experience school failure. Despite natural ability, their inattentiveness, impulsivity, and hyperactivity often result in failing grades, not being promoted to the next grade, suspension, and expulsion. Without proper diagnosis, accommodations, and intervention, children with ADD/ADHD are more likely to experience negative consequences.

> **The child with ADD/ADHD will benefit from immediate feedback (for example, is the parent—or teacher—angry or pleased?).**

10. What can schools do for children with ADD/ADHD?

Children suspected of having ADD/ADHD must be evaluated at the school's expense and, if found to be eligible, provided services under either of two federal laws—the Individuals with Disabilities Education Act (IDEA) or Section 504 of the Rehabilitation Act of 1973. Some of the services that could be provided to eligible children include modified instructions, assignments, and testing; assistance from a classroom aide or a special education teacher; assistive technology; behavior management; and the development of a positive behavioral intervention plan.

11. How can I help my child make friends?

Almost any program teaching social behaviors involves some form of modeling—that is, demonstrating appropriate behavior so that the child learns by imitation. Role modeling includes using forceful and interesting verbal cues when speaking, reinforcing good behaviors, greetings at the door, and appropriate smiles and gestures. For younger children, puppets can be appropriate models.

A key part of modeling involves the use of good affective (emotion-related) skills and body language. Children with ADD/ADHD may have problems understanding facial expressions; if they are taught how to read the emotions behind such facial expressions, the child's understanding of social interaction may improve.

The child with ADD/ADHD will benefit from immediate feedback (for example, is the parent—or teacher—angry or pleased?). Strong affective gestures (winks, thumbs up, frowns, etc.) also communicate effectively to the child.

The parent who uses direct, encouraging praise will promote good social response. Encouraging praise places the value on the

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child's effort, not the quality of outcomes. For example: "I bet you really worked hard on that one." The praise does not judge quality, but specifically states that the child did well. Do not focus on what the child can't do, but instead focus on the child's strengths and abilities.

12. How can I make my child behave?

Provide clear, consistent expectations, directions and limits. Children with ADD/ADHD need to know exactly what others expect from them. They do not perform well in ambiguous situations that require determining "shades of gray" or "reading between the lines."

> **If a public school is unable to provide an appropriate education for a child, then the school district may place a child with disabilities in a private school setting at public expense.**

Set up an effective discipline system. Parents may need to learn proactive discipline methods that teach and reward appropriate behavior and respond to misbehavior with alternatives such as "time-out," natural consequences, and loss of privileges.

Create a behavior modification plan to change the most problematic behaviors. Behavior charts and other behavior modification techniques will help you focus on and address problems in systematic, effective ways. Learn to use behavior modification principles to reinforce positive behaviors and to eliminate or reduce negative behaviors that create problems for your child.

Assist your child with social issues. Children with ADD/ADHD may be rejected by peers because of hyperactive, impulsive, or aggressive behavior. Parent training can help you assist your child in making friends and learning to work cooperatively with others.

Identify your child's strengths—in areas such as art, computers, mechanical ability—and build upon these strengths so that your child has a sense of pride and accomplishment.

Set aside a daily "special time" for your child. Constant negative feedback can erode a child's self-esteem, while a daily dose of TLC—whether a special outing or just time spent in positive interaction—can help fortify your child against assaults to his or her self-worth.

Seek support for yourself. Parents can give each other information as well as support. Since ADD/ADHD is highly hereditary, many parents of children with ADD/ADHD discover when their child is diagnosed that they too have ADD/ADHD. Parents with ADD/ADHD may need the same types of evaluation and treatment that they seek for their children.

13. My son has been suspended again. What should I do?

The Individuals with Disabilities Education Act (IDEA) has two important offerings for children with behavioral problems. Even when suspended or expelled, children covered by IDEA are still entitled to education services that meet the standards of a free appropriate education. Parents can request an impartial due-process hearing when they disagree with the school's decision in such matters. Under a separate provision, the child can remain in the then-current educational placement until all administrative proceedings are concluded (with the exception of cases in which the child has brought a weapon or drugs to school, or is proven to be substantially likely to cause harm.

IDEA also requires that if a child's behavior interferes with learning, a Functional Behavior Analysis be conducted and a Positive Behavior Plan be developed. IDEA prohibits schools from suspending for more than ten days and expelling students whose behavior results from their disability—unless drugs or weapons are involved or the child poses a danger to anyone. Parents with questions about school actions or their child's legal rights, can contact the Parent and Training Information Center for their state [*Editor's Note: to identify the center in your state, contact Alliance Coordinating Office by telephone at (612) 827-2966, by fax at (612) 827-3065, by e-mail at alliance@taalliance.org, or through their Web site at http://www.taalliance.org*].

14. Where can I find a school for children with ADD/ADHD?

Seeking special education or 504 services for a child with ADD/ADHD can often eliminate the need for a private school by making a child's public school experience more successful. Some parents, however, may want to locate a school specifically tailored to serve children with learning differences. Parents can learn about such schools and education programs from talking to parents at local CHADD chapter meetings, commercial private school compendiums, or from the school counselor.

If a public school is unable to provide an appropriate education for a child, then the school district may place a child with a disability in a private school setting at public expense.

15. Is ADD/ADHD overdiagnosed?

Because ADD/ADHD has received so much media attention in recent years and the public is more aware that it exists, some fear has arisen that it is overdiagnosed. The Council on Scientific Affairs of the American Medical Association recently investigated this issue and determined that such is not the case. However, some evidence exists that minority students may be disproportionately identified for special education in some categories, including behavior disorders, serious emotional disturbance, and mental retardation. The National Medical Association has raised concerns that African American children are also being overdiagnosed as having ADD/ADHD.

16. Where can I get the name of a professional in ADD/ADHD in my area?

Though CHADD's national office is unable to make professional referrals, members of local CHADD chapters can offer a great deal of guidance in determining the best places in your area to seek diagnosis and treatment. They may have a list of professionals in your area available. The chapter nearest you can be found through the chapter locator on the CHADD Web site (http://www.Chadd.org) or by calling the national office at (301) 306-7070.

Local chapters are also excellent sources of support, encouragement and information. Many adults with ADD/ADHD and parents of ADD/ADHD children attend local meetings. They have been in situations similar to yours and can share the steps they have taken to manage ADD/ADHD successfully. ■

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Circle #27

Special Report — PART THREE

NEWBORN SCREENING

Newborn Screening and Parent Support Groups

by Kathy Stagni

Could it have been different? We will always wonder if life would have been different had newborn screening been available 11 years ago when my daughter Melissa was born with propionic acidemia (PA). Melissa was born on November 11, 1998, with an acute case of PA, an inborn error of metabolism that is so rare, the incidence rate is only about 1 in 50,000. Her metabolic doctor told us we would probably have better odds of hitting the jackpot in Las Vegas.

Even if the latest technology for screening newborns at birth, tandem mass spectrometry, had been available then, most likely it would not have saved Melissa from her initial episode. The onset of PA caused a coma, high ammonia levels in her blood, and brain swelling, resulting in mild mental retardation, speech delays, and the need for continuous feeding of a special low-protein formula through a nasal-gastric tube.

We will never know if Melissa's outcome could have been prevented, but we believed we could make a difference for others. My mission for the last three years has been to help families connect and provide mutual support through a newsletter and the Internet. Three years ago, I took over the Organic Acidemia Association (OAA). Started by Lorie Asten-Neilson, OAA is a small, grassroots parent support group that has been in existence since the early 80s. OAA represents more than fifteen different organic acidemias, which involve the body's inability to break down protein.

"WE ARE NOT ALONE"

I had heard of OAA from my daughter's metabolic doctor shortly after her diagnosis, but out of denial, I did not contact them immediately. When I did, the OAA newsletter became the only outlet I had to share my feelings and experiences and learn about other families dealing with the same situation. Through the newsletter we even met a few families, some living in Minnesota as we do. That sense of connecting is very important in raising a child with a metabolic disorder. Parents have the knowledge and experience

Top: The Stagni family (l-r)—Kathy, Lee, and Melissa. Above: Melissa Stagni, 11, was born with propionic acidemia (PA).

Sponsored in part by an unrestricted grant from Sigma Tau Pharmaceuticals, Inc.

to help other families deal with the day-to-day problems that can occur while caring for a child with such life-threatening disorders. We have experienced so many similarities among these children that the sense of relief we feel in knowing we are not alone is one of the few emotional supports we have in dealing with such a rare disorder. I will never know the heartache of losing a child because of misdiagnosis, but I do know the heartache of raising a child with special needs and always wondering "what if?"

When the Internet began to get popular, I started to communicate via e-mail with a family living in Massachusetts who has a daughter with PA. I thought it was wonderful to be able to share ideas and stories with others who could relate, and we both thought it would be great to share our stories more widely on the Internet. The previous director of OAA was eager for my assistance, and I suddenly found myself as the executive director of the group. We started a Web site and began hearing from parents all over the world who had children with rare metabolic disorders.

OAA is starting to see positive benefits from expanded newborn screening. Just over a year ago, when their son, Mubashir, was born, the Younis family lived in Massachusetts, a state that has implemented expanded screening that includes organic acidemia disorders. The very day that the family learned that Mubashir was diagnosed with PA, they contacted the OAA over the Internet. Waheed Younis claims that Mubashir is doing better than any other PA kid that he knows about, something he credits to early intervention and expanded newborn screening! Waheed also praises the OAA's mission. "The OAA gave me lots of emotional support," he said. "Knowing that we are not alone makes it easier to accept the challenges. And we've also received lots of useful information that helps us manage Mubashir each and every day."

Jordan Franks had a metabolic crisis four days after he was born. He was diagnosed with PA, a disorder that is not screened for in Illinois, where the Franks family live.

JORDAN FRANKS

Other families are not as fortunate. Jill Franks lives in Chicago, Illinois, where newborn screening has not been expanded. This past February, when her son Jordan was just 4-days-old, he had a metabolic crisis. Jill remembers bringing Jordan to the emergency room, where the doctors struggled to reach a diagnosis. Jordan's ammonia level went to 550 (10 times the normal range), which can lead to permanent brain damage. He was initially diagnosed with methylmalonic acidemia, and a day later the diagnosis was revised to PA when the lab results were completed. Jill often wonders if newborn screening would have identified the disease before Jordan's metabolic crisis. Jill says, "Words cannot express how much the support from OAA parents has meant to me and my family, including my mother. I have never encountered such an amazing group of positive peo-

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Michael A. Metil, 6, was born with glutaric acidemia (GA). The two Amish sisters pictured with him were also born with GA.

Mubashir Younis,1, was diagnosed with PA very early, thanks to the expanded newborn screening in Massachusetts. His parents credit Mubashir's health today to early detection.

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ple. Every time I read the OAA newsletter, I relive the first days of Jordan's life. As the saying goes, the names have changed but the story remains the same. OAA parents are more than new friends, they are like new family members. They gave me, and continue to give me, invaluable information on getting therapy early and often, what to expect, reminders that 'it will get better,' and treatment plans. I only hope that I can be as helpful to new parents facing a diagnosis of PA."

LISTENING TO THE STORIES

Cay Welch and her husband Mike Metil started a separate support group, International Organization for Glutaric Acidemia (IOGA), when their son Michael was born six years ago. Their group focuses on Michael's specific organic acidemia, glutaric acidemia type 1, a disorder that has a high incidence rate in the Amish community. Cay tells a wonderful story about meeting Carla, a 17-year-old Amish girl. When they met, Carla sat almost proudly in her wheelchair, although, Cay said, "She had to be all of 95 pounds—soaking wet." Able to communicate only by moving her headband pointer, Carla fired off question after question. She told Cay her story of self-diagnosis, which began in the library and grew in chat rooms on the Internet discussing rare metabolic disorders. Soon after matching her symptoms with those typical of GA, she had an explanation for her mysterious headaches, muscle weakness, and nausea when digesting meat. Carla asked her mother to contact a clinic in Pennsylvania that she had found during her research, and she and her mother then traveled from New York State to Strasburg, Pennsylvania, to see Dr. Holmes Morton at The Clinic for Special Children. Carla's diagnosis also gave the family answers to why Carla's baby brother, Johnnie, was not sitting, crawling, or talking at 18 months old. Then there was the unexplained death of a sibling which was diagnosed as sudden infant death syndrome (SIDS). Did Johnnie and the baby with SIDS have GA? Newborn screening could have easily detected GA in this entire family and offered an opportunity for early intervention.

Cay tells another story, too, about Barbie Ann and her sister Lydia. In their matching blue and black pinafore dresses, they looked almost like twins, giggling, playing, and running barefoot through the yard where the Amish children bounded about. Shy but curious, they spoke some English and asked Cay what was wrong with Michael. "Why does he eat from a tube in his belly?" they asked. "Doesn't he drink the same milk we do?" Cay answered, "Yes, but Michael had much brain damage when he was 11 months old and did not fare as well as you did." The moment of realization that they had prospered, not suffered, despite their rare disorder was powerful for the Amish girls. And all because an expanded screen was made available at birth: a home birth, no less, which is common among Amish women. Cay adds, "Although I cannot rescue my son or wave a magic wand saying, 'This will all be better, Michael,' I can and do aid others through our IOGA Web site, newsletters, co-sponsoring medical conferences, linking families, and advocating the expanded newborn screening for every state."

Organic acidemia disorders are highly manageable with diet and medication. Children who inherit these diseases are able to lead happy and productive lives. Newborn screening can improve their lives through early detection and intervention. It must be mandated across the United States as quickly as possible. Yes, my life is different from families with "normal" children, but I do feel my life has brought on a new meaning by having a child with a metabolic disorder. As Erma Bombeck wrote in her poem, "God chooses moms of special needs children for a purpose." My purpose is to give Melissa the best quality of life she can have and to help support and connect the families that live with children with metabolic disorders.

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Phone: (800) 336-GENE
Web site: http://www.geneticalliance.org

Serving the Family From Birth to the Medical Home

Newborn Screening: A Blueprint for the Future

Executive Summary: Newborn Screening Task Force Report

A Report From the Newborn Screening Task Force Convened in Washington, DC, May 10-11, 1999.

SPONSORING ORGANIZATIONS:
Health Resources and Services Administration • American Academy of Pediatrics
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Approximately 4 million infants are born yearly in the United States (US), and are screened to detect conditions that threaten their life and long-term health. Newborn screening is a public health activity aimed at the early identification of infants who are affected by certain genetic/metabolic/infectious conditions. Early identification of these conditions is particularly crucial, as timely intervention can lead to a significant reduction of morbidity, mortality, and associated disabilities in affected infants.

Newborn screening has been universally accepted for the past 3 decades. It represented the first population-based genetic screening program, and signaled the integration of genetic testing into public health programs. Today, new advances in technology are making possible new forms of newborn screening programs, such as newborn hearing screening. These technological advances will continue to have a significant impact on the sensitivity, specificity, and scope of newborn screening programs, including newborn heelstick screening.

Challenges are anticipated with technological advances. It is likely that public pressure to deploy new diagnostic capabilities, such as DNA-based technology, will increase despite limited knowledge of potential risks and benefits. In addition, the ability to detect individuals with conditions for which there is no effective or necessary treatment is likely. Further, as the Human Genome Project is completed, the impetus and opportunity for the transition of genetic technology into practice will increase. These and other challenges will affect not only newborn screening tests, but also the entire newborn screening system, which includes short-term follow-up, diagnosis, treatment/management, and evaluation. Inherent to each of these components is an education process. A national dialogue and process is needed to support state newborn screening systems as they try to keep pace with new technology.

To address these and other issues, a National Task Force on Newborn Screening (Task Force) was convened by the American Academy of Pediatrics (AAP) with funding from and at the request of the Maternal and Child Health Bureau (MCHB), Health Resources and Services Administration (HRSA), and the US Department of Health and Human Services (HHS). The AAP was asked to convene the Task Force in recognition that pediatricians and other primary care health professionals must take a lead in partnering with public health organizations to examine the many issues that have arisen around the state newborn screening programs.

To ensure that children who are screened are linked to a medical home, it was essential that pediatricians and other primary care health professionals be involved. The AAP defines the medical home as care that is accessible, family-centered, continuous, comprehensive, coordinated, compassionate, and culturally competent. A child who has a medical home has a pediatrician or other primary care health provider who is working in partnership with the child's family to ensure that all medical, non-medical, psychosocial, and educational needs of the child and family are met in the local community.

Task Force members were appointed to represent many perspectives among those who operate programs, conduct research, and are affected by newborn screening systems. The co-sponsors of this effort were: other HHS agencies including the National Institutes of Health (NIH), the Centers for Disease Control and Prevention (CDC), and the Agency for Healthcare Research and Quality (AHRQ); the Genetic Alliance, which is a consortium of consumer groups; and national public health organizations including the Association of State and Territorial Health Officials, the Association of Maternal and Child Health Programs, and the

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Association of Public Health Laboratories. This report has been approved by the AAP Board of Directors. It does not necessarily reflect the viewpoints of sponsoring organizations or the organizations represented by members of the Task Force.

The purpose of the Task Force was to review issues and challenges for state newborn screening systems. The review process was structured to further expand representation. Task Force members were divided into five work groups, and additional individuals were invited to participate in each work group's examination of key issues. Over the course of six months, questions, concerns, and issues were collected from state public health agencies, state public health laboratory directors, maternal and child health programs, pediatricians, and other primary care health professionals who care for children, families and other consumers, bioethicists, scientists, and health service researchers. Each work group formulated conclusions and developed consensus recommendations. On May 10-11, 1999, the Task Force heard presentations from the five work groups, along with public comment on the reports and recommendations. A set of recommendations was developed incorporating key elements of the work group reports, issues raised by the public, and other related information. This document summarizes the Task Force recommendations.

The Task Force has outlined a national agenda for strengthening each "state" newborn screening system. ("State" newborn screening systems refer to state and territorial programs for heelstick newborn screening.) The Task Force believes that public health agencies (federal and state), in partnership with health professionals and consumers , should continue to:

- Better define public health responsibilities for federal and state public health agencies;
- Develop and disseminate model state regulations to guide implementation of state newborn screening systems (including disease and test selection criteria);
- Develop and evaluate innovative testing technologies;
- Design and apply minimum standards for newborn screening activities (e.g., sample collection, laboratory quality, sample storage, and information systems);
- Develop and disseminate model follow-up, diagnosis, and treatment guidelines and protocols for health professionals, and other participants in the newborn screening system;
- Design and evaluate model systems of care with services and supports from infancy to adulthood that are consistent with national guidelines for children with special healthcare needs (i.e., family-centered, community-based, and coordinated systems of care.
- Design and evaluate tools and strategies to inform families and the general public more effectively; and
- Fund demonstration projects to evaluate technology, quality assurance, and health outcomes.

KEY RECOMMENDATIONS

I. Effective Newborn Screening Systems Require an Adequate Public Health Infrastructure and Must Be Integrated With the Healthcare Delivery System

- Federal agencies must take action to strengthen the public health infrastructure for newborn screening.
  - —The federal government—acting through the HRSA, CDC, Health Care Financing Agency (HCFA), AHRQ, NIH, and other agencies—should collaborate to provide ongoing leadership and support for development of newborn screening standards, guidelines, and policies.
  - —As the federal unit with most responsibility for newborn screening system development, the HRSA should engage in a national process involving government, professionals, and consumers to advance the recommendations of this Task Force and assist in the development and implementation of nationally recognized newborn screening system standards and policies.
  - —Federal resources should be identified to sustain a Newborn Screening Quality Assurance Program to assist state public health laboratories. Such assistance must be both sustained and expanded as states adopt new screening technologies and modalities.
  - —The HRSA's MCHB should strengthen current mechanisms to improve coordination of infant health programs and initiatives within the state and/or between states, including continuation of funding in support of newborn screening program reviews.

- State public health agencies should direct their newborn screening program to be consistent with professional guidelines and recommendations. Each state public health agency should take responsibility for systems development. Specifically, states and their agencies have responsibility to:
  - —Design and coordinate the newborn screening system;
  - —Adhere to nationally recognized recommendations and standards for validity and utility of tests. State newborn screening systems have a responsibility to review the appropriateness of existing tests, tests for additional conditions, and new screening technology and modalities; and
  - —Adopt standards for laboratories, health professionals, and healthcare financing based on nationally recognized standards and guidelines for follow-up diagnosis, and treatment.

- State public health agencies, working under legislative authority, have the ongoing responsibility to ensure quality and evaluate program effort. States and their public health agencies should:
  - —Maintain a newborn screening system that has appropriate evaluation, performance monitoring, and quality assurance activities from initial screening, through follow-up, diagnosis, treatment, and services through adolescence and adulthood;
  - —Conduct oversight of program operations, including those outside the public health agency, such as test analysis and tracking, private sector collection and transmission of screening data, laboratory quality, and the quality of the diagnostic procedures and treatment programs at pediatric subspecialty clinics; and

—Monitor and evaluate program performance through collection, assembly, analysis, and reporting of data, including outcome evaluations.

•States and public state health agencies should implement mechanisms to inform and involve health professionals and the public. Each state should:

—Develop a program advisory board that is multidisciplinary, involves pediatricians and other primary care health professionals who provide medical homes for children, pediatric subspecialists, and has meaningful representation of families and the general public; and

—Design and implement public, professional, and parent education efforts regarding newborn screening.

•States and state public health agencies should provide support for coordination and integration of program activities, including information and services. This will require public—private, federal—state and intrastate partnerships. States should:

—Use public and private resources to fund demonstration programs that can serve as a testing ground for linking information and service in ways that improve the newborn screening system; and

—Structure interagency coordination to maximize resources and to improve the efficiency and effectiveness of newborn screening systems.

II. Public Health Agencies Must Involve Health Professionals, Families, and the General Public in the Development, Operation, and Oversight of Newborn Screening Systems

•The pediatrician or primary care health professional who, in partnership with parents, is the source of the child's medical home, should:

—Ensure that all newborns admitted to their practice have received adequate newborn screening, and that appropriate documentation of testing is present;

—Follow positive screening results to diagnosis (i.e., confirmed or excluded), including repeated screening and diagnostic testing;

—Coordinate a seamless system of care with pediatric subspecialty clinics, tertiary care centers, and/or community-based providers, when a child is diagnosed with a disorder through newborn screening;

—Maintain a central record and database containing all pertinent medical information about the child. This record should be accessible to the family and others involved in the child's care, but confidentiality must be ensured; and

—Assist the family in understanding the diagnosis, symptoms, and potential implications of a diagnosed genetic/metabolic condition, as well as the availability of genetic counseling, family testing, and other family support services.

•Parents should receive information (on behalf of their children) about newborn screening.

—Prospective parents should receive information about newborn screening during the prenatal period. Pregnant women should be made aware of the process and benefits of newborn screening and their right of refusal before testing, preferably during a routine third trimester prenatal care visit.

—Parent knowledge should be reinforced after delivery by educational materials and discussion as needed by the infant's pediatrician or primary care health professional and/or knowledgeable hospital staff.

—Prenatal health care professionals as well as the infant's primary care health professional should be knowledgeable about their state's newborn screening program through educational efforts coordinated by the state's newborn screening program in conjunction with the a newborn screening advisory body.

•Written documentation of consent is not required for the majority of newborn screening tests, for example, those tests of proven validity and utility.

—Parents should always be informed of testing and have the opportunity to refuse the testing.

—If after discussions about the newborn screening with health professionals, parents refuse to have their newborn tested, this refusal should be documented in writing and honored.

—If a newborn screening test is investigational or in the process of being developed, the benefits or potential risks have yet to be demonstrated, and identifiers are not removed from the specimen, informed consent should be obtained from parents and documented.

•Studies should be performed to broaden understanding of the ways in which communication can be performed more effectively for the benefit of consumers.

—Pilot studies and evaluation research should be conducted to assess the potential impact of revised parental permission and informed decision-making policies.

—Each state or region should, with input from families who have children with special needs and/or parent information centers, develop and provide family educational materials about newborn screening.

—Evaluation of materials should be ongoing, particularly because of the changing demographics of childbearing, cultural changes, and rapid developments in genetic science.

•Parents have a right to confidentiality and privacy protection for the medical and genetic information in any type of newborn screening results. Based on nationally recognized standards and guidelines, each state should have appropriate policies and mechanisms in place to ensure families' privacy and confidentiality. Laws to guarantee genetic privacy and protect against genetic discrimination should benefit patients identified by newborn screening.

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- States and the federal government should include public participation in medical policy-making. The Secretary's Advisory Committee on Genetic Testing provides a mechanism for public participation in genetic policy development at the federal level. Each state should establish and fund a newborn screening advisory body with public participation to advise on newborn screening policy developments.
  - —Such an entity should include a broad range of public advisors representing parents, health professionals, third-party payers, appropriate government agencies, and other concerned citizens.
  - —Such an entity should be empowered to advise state officials about screening for particular conditions based on accepted standards and be consulted about the development of related state regulations.
  - —Such an entity should be involved in the review of new tests under consideration by the state and in the development of related state regulations.
  - —Such an entity should be involved in the ongoing evaluation of all aspects of the state's process for newborn screening. Oversight activities should include a review of: testing, follow-up, and treatment efforts; the impact on families receiving false-positive screening result; and the state's process for handling consumer input including grievances.

III. Public Health Agencies Must Ensure Adequate Infrastructure and Policies for Surveillance and Research Related to Newborn Screening

- State Maternal and Child Health (MCH) programs should conduct a review of the newborn screening system and its relationship to the HRSA MCH Block Grant Performance Measures and evaluate the quality of data of the newborn screening-related performance measures.
- The federal HCFA should develop Health Plan Employer Data and Information Set (HEDIS) measures to evaluate the health plan's performance within the newborn screening system.
- A federally-funded newborn screening research agenda should be outlined that aims to: develop better tests (more sensitive, more specific, and less costly); assess the validity and utility of new technologies (eg, tandem mass spectrometry, DNA-based testing, and other evolving technologies); and define appropriate uses of residual biologic samples for population-based research and surveillance.
- The HRSA's MCHB should provide grants to states to stimulate development of newborn screening information systems, with a focus on newborn screening systems that are connected to the medical home, newborn screening process and outcome evaluation, development of standardized data sets, analysis of cost-efficiency and effectiveness, and integration with other public health data systems. Support for technological innovation (i.e., new test technologies) should include these measures.
- Pediatricians, pediatric subspecialists, and other health professionals who care for children should contribute to newborn screening data collection to advance knowledge about health outcomes and intervention effectiveness. Professional associations, the HRSA-funded National Newborn Screening and Genetics Resource Center and state newborn screening programs should develop strategies to assist health professionals in their efforts to participate in and learn from newborn screening information systems.
- Pilot studies should be undertaken to demonstrate the safety, effectiveness, validity, and clinical utility of tests for additional conditions and new testing modalities. Informed consent of parents is called for in all such pilot studies. These studies might be undertaken by individual states, regional or nationwide groups of states, or through federal grants provided to research institutions across the country.
- Federal and state public health agencies, in partnership with health professionals, families, and representatives of ethnic, minority, and other diverse communities should:
  - —Develop model legislation and/or regulation that articulates policies and procedures regarding utilization of unlinked and identifiable residual samples for research and public health surveillance. This process should include the review and consideration of the recent recommendations to the President set forth by the National Bioethics Commission (NBAC) for research involving human biological materials;
  - —Develop model consent forms and informational materials for parental permission for retention and use of newborn screening samples;
  - —Develop educational materials for parents that includes information regarding the storage and use of residual samples;
  - —Organize collaborative efforts to develop minimum standards for storage and database technology to facilitate appropriate storage for residual newborn screening blood samples at the state level; and
  - —Consider creating a national or multi-state population-based specimen resource for research in which consent is obtained from the individuals from whom the tissue is obtained. Such a resource could be an alternative to retaining newborn screening samples for potential use in research.

- Using national recommendations, each state program should develop and implement policies and procedures for retention of residual newborn screening blood samples that articulate the rational and objectives for storage, the intended duration of storage, whether storage is with or without identifiers, and guidelines for use of identifiable and unlinked samples. An advisory group for newborn screening programs with broad health and family/community representation is a valuable resource in developing policies and procedures and in reviewing applications for use of retained samples. The advisory body also could determine priorities for use.

IV. Public Health Agencies Should Ensure Adequate Financing Mechanisms to Support a Newborn Screening Program

- State should ensure adequate financing of all parts of the newborn screening system: screening, short-term follow-up, diagnostic testing, comprehensive medical care/treatment, and evaluation of the system. If newborn screening fees are not adequate, funding of all components of the system could be accomplished with other public health dollars or by third-party payers. Other uses of newborn screening fees should not be considered until all of the components of the newborn screening system are fully funded.
- States should take responsibility for blending resources available through the Title XIX (Medicaid), Title V (MCH Block Grant), Title XXI (State Children's Health Insurance Program) [SCHIP], and private insurance to guarantee necessary coverage and financing for all children and adolescents with a condition diagnosed through the newborn screening system.
- State contracts for publicly-subsidized third-party insurance plans that cover children (e.g., Medicaid and SCHIP) should explicitly require coverage for newborn screening and those services and treatment related to disorders identified by newborn screening. State contracts also should require that third-party payers ensure access to healthcare professionals with appropriate pediatric expertise within the network or through out-of-network referrals.
- States, in cooperation with health professionals and payers, should put mechanisms in place to identify the third-party payers for all newborns immediately following birth. For example, all states should operationalize the automatic newborn eligibility requirements under Medicaid and the Health Insurance Portability and Accountability Act (HIPAA) newborn coverage provisions that require infant coverage and prohibit preexisting condition exclusions for newborns.
- Purchasers—public and private—should ensure that the benefits package they pay for includes the care and services defined by the AAP Scope of Health Care Benefits Statement and the Council of Regional Networks for Genetic Services Guidelines.
- In the Supplemental Security Income (SSI) program, the federal government should review the technical appropriateness of guidelines, and evaluate the consistency of their application, for children with conditions identified through newborn screening. ■

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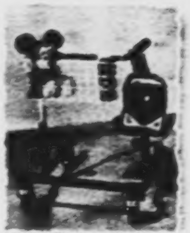
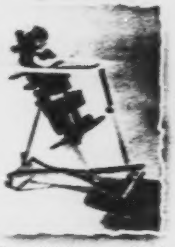

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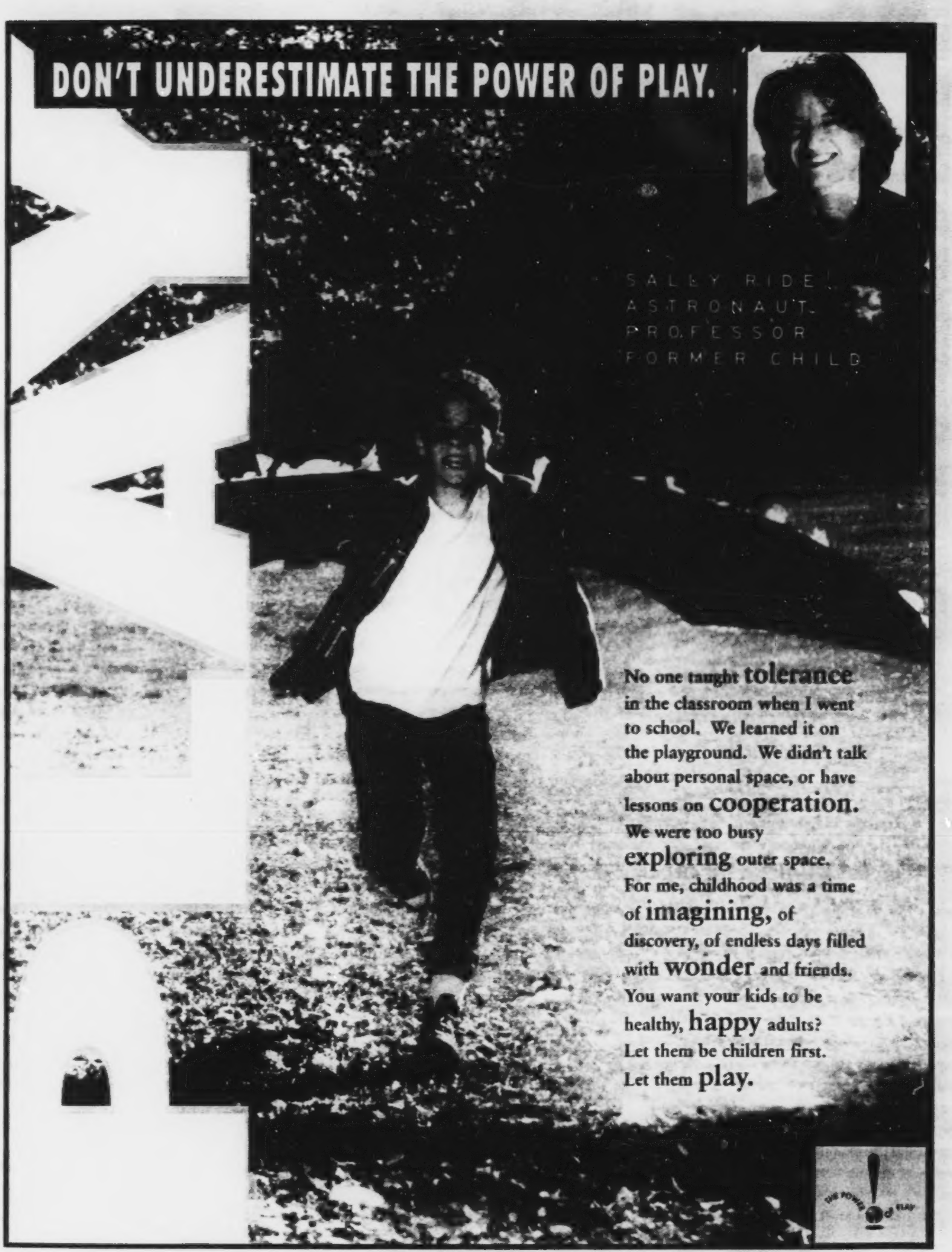

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Parents as Partners in the Medical Home, Part 2

Choosing a Pediatrician

Partners In The Medical Home Project

Contributors:
David Hirsch, MD, FAAP,
Diana Frieberg, BSN
Mae Moore
Phoenix Pediatrics, Ltd.
Judie Walker
Raising Special Kids

Not all physicians are prepared to treat all children who have complex chronic physical and health problems. Some healthcare providers are reluctant to work with these children because they lack knowledge and experience. Others are concerned about getting reimbursed for the additional time involved in caring for children with these special needs. Still others question the value of various tests and treatments. As a result, many families have to search for doctors who are ready, willing, and able to care for their children.

Finding a qualified, responsive physician is just one part of the families' quest for medical services. Families also have extensive interactions with medical staff. Receptionists, nurses, care coordinators, and x-ray technicians fill many functions, including answering the phone, communicating information to the physician, administering lab tests, assisting during the examination, making referrals, and negotiating with managed-care personnel. As a result, the skillfulness and attitudes of the medical staff also have a significant impact on the family's level of stress and sense of satisfaction. Selecting a pediatrician should include consideration of the qualities of the medical support staff.

What qualities are needed by pediatricians and staff serving families and children with special healthcare needs?

A team of parents and professionals collaborated in order to systematically define the qualities that make pediatricians and their staff effective in working with families and children with serious, complex physical and health problems. The team included parents participating in the Parents as Partners in the Medical Home Project*. The Medical Home is a recently developed model of pediatric healthcare (as defined by the American Academic of Pediatrics and the Maternal Child Health Bureau) in which providers ensure that children and their families have medical and non-medical services that are accessible, continuous, comprehensive, and coordinated in a compassionate and culturally competent manner. The Medical Home concept emphasizes that families play an active role on the medical team, and that they be recognized as partners in caring for their children.

The families who participated on the team are all residents of Arizona and were representative of the state's diverse population. Families included those of African-American, Anglo, Latino, and Native American backgrounds. They have children ranging from 17 months to 24 years with Down syndrome, reactive airway disease, autism, metabolic disorders, myelomenengocele, cerebral palsy, epilepsy, congenital heart disease, and developmental delays. Most of the children have multiple conditions. The professional members of the team included pediatrician David Hirsch, MD, and Clinical Care Coordinator Diana Frieberg, BSN, both of Phoenix Pediatrics, Ltd.; special education faculty from Arizona State University (and authors of this article) Tanis Bryan, PhD, and Karen Burstein, PhD; and a parent/professional Judie Walker, of Raising Special Kids. Raising Special Kids is a statewide grassroots organization of parents of children with disabilities that provides parent training, support services, and information dissemination statewide.

Correction: In the previous issues the authors Tanis Bryan, PhD, and Karen Burstein, PhD, were incorrectly identified as being with the University of Arizona. Both authors are faculty members at the **Arizona State University, Tempe**. We sincerely apologize for the error and any inconvenience this may have caused.

Defining the qualities that make pediatricians and staff effective for children with special healthcare needs

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[redacted]

The team met monthly in its study of healthcare providers for children with special healthcare needs. They reviewed related research, most of which focused on physicians' communication styles during medical interviews. Although communication skills are clearly a critical component of the physician's effectiveness, team discussions led to a much broader view of necessary physician characteristics. The team extended the discussion to include quality indicators of the medical staff (e.g., cheerfully greets caregiver and child by name) and the medical practice (e.g., phone system allows access to medical staff within reasonable time). The factors that parents identified as critical in physicians and staff serving children with special healthcare needs were assembled into the Survey *Quality Indicators of an Effective Pediatrician for Children with Special Healthcare Needs* (see Table 1 on the following page).

The Survey Quality Indicators of an Effective Pediatrician for Children with Special Healthcare Needs can be a useful tool for parents and caregivers as well as physicians and staff.

Pediatricians who are perceived by families as effective with children with special

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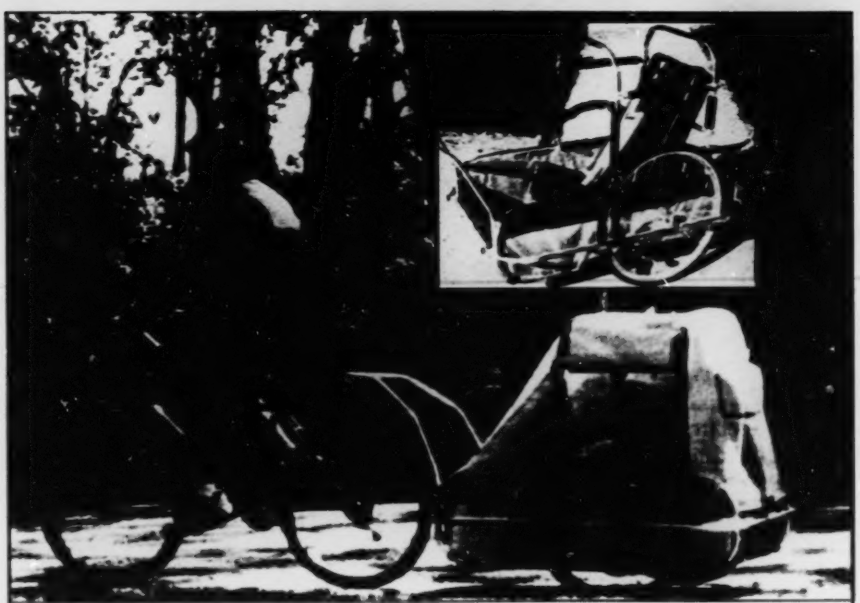

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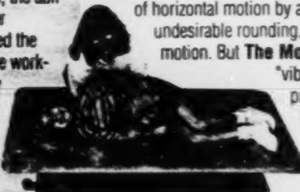

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QUALITY INDICATORS OF AN EFFECTIVE PEDIATRICIAN FOR CHILDREN WITH SPECIAL HEALTHCARE NEEDS

This survey is a tool to help evaluate the quality of care received from your child's healthcare provider. Parents/Caregivers of children with special healthcare needs identified these traits as important to quality of care. Please respond to each item by indicating whether your child's healthcare provider exhibits these behaviors:

1= ALMOST ALWAYS 2= SOMETIMES 3= HARDLY EVER 4= ALMOST NEVER.

Please feel free to add your comments, explanations, or any additional information that you believe will help us improve the quality of care for children. Thank you in advance for completing this survey.

Child's Age ______Child's Gender ______________Name of Healthcare Provider ____________________________

Type of Services Provided ____

Type of Visit: ☐ Routine ☐ Emergency ☐ Follow-up

My child's physician:

ATTITUDE

Responds to child's needs first	1	2	3	4
Shows empathy to child and family	1	2	3	4
Is nonjudgmental	1	2	3	4
Gives families realistic reasons to be hopeful and optimistic	1	2	3	4
Involves family in finding solutions	1	2	3	4
Invites and responds positively to family's ideas and suggestions	1	2	3	4

COMMUNICATION SKILLS

Is a good listener	1	2	3	4
Has direct eye contact with child and Parent/Caregiver	1	2	3	4
Asks questions to refresh Parent/Caregiver's memory	1	2	3	4
Encourages Parent/Caregiver and child to ask questions	1	2	3	4
Responds to family's communication style	1	2	3	4
Uses familiar terminology or carefully defines new terms	1	2	3	4
Speaks to the child even if child cannot respond verbally	1	2	3	4
Touches child when necessary	1	2	3	4
Has a gentle touch	1	2	3	4
Explains treatment in detail	1	2	3	4
Checks to make sure Parent/Caregiver understands instructions	1	2	3	4
Makes statements that are sensitive and appropriate	1	2	3	4

INTERPERSONAL STYLE

Takes time and does not seem rushed	1	2	3	4
Provides encouragement to child and Parent/Caregiver	1	2	3	4
Provides open minded feedback to child and Parent/Caregiver	1	2	3	4
Collaborates with child and Parent/Caregiver in seeking solutions	1	2	3	4
Is not defensive	1	2	3	4
Shows patience	1	2	3	4
Is respectful of Parent/Caregiver experience and knowledge of the child	1	2	3	4
Trusts the Parent/Caregiver	1	2	3	4
Is compassionate and kind hearted	1	2	3	4
Suggests ways that Parent/Caregiver an improve in taking care of child	1	2	3	4
When appropriate, assures Parent/Caregiver that he/she is doing a good job in caring for the child	1	2	3	4
Provides extra TLC through giving such things as "special" bandages, hard candy, stickers	1	2	3	4
Takes Parent/Caregiver' concerns seriously	1	2	3	4
Shows personal involvement and interest in the family	1	2	3	4

KNOWLEDGEABLE

Listens to all symptoms before making a diagnosis	1	2	3	4
Is knowledgeable about child's condition, past and current status	1	2	3	4
Is very knowledgeable about diagnoses and current treatments	1	2	3	4
Is up to date on current medications	1	2	3	4
Gives options for solving problems	1	2	3	4
Volunteers information about agencies that provide additional services	1	2	3	4
Knows how to access other agencies that provide services	1	2	3	4
Follows through on care	1	2	3	4
Follows up on outcomes	1	2	3	4
Stays current with recent research	1	2	3	4

MEDICAL SUPPORT STAFF

Cheerfully greets Parent/Caregiver and child by name	1	2	3	4
Informs Parent/Caregiver about actual wait time	1	2	3	4
Introduces self and explains role	1	2	3	4
Talks to child even if child is not verbal	1	2	3	4
Explains the procedures	1	2	3	4
Explains what is expected of the child during the examinations or procedure	1	2	3	4
Talks the child through the procedure	1	2	3	4
Takes direction from the child	1	2	3	4
Validates the child's feelings (e.g., fear, pain)	1	2	3	4
Reviews chart and medications	1	2	3	4
Uses appropriate prompts and reinforcers	1	2	3	4
Is comfortable touching the child	1	2	3	4
Does thorough and accurate assessment of the child	1	2	3	4
Says good-bye	1	2	3	4

MEDICAL PRACTICE

Staff has low turn-overt	1	2	3	4
Phone system allows access to medical staff in reasonable time	1	2	3	4
Staff uses consistent procedures for handling children (e.g, weighing, disrobing)	1	2	3	4
Staff notifies Caregiver/ Parent in advance about billing problems	1	2	3	4
Staff writes co-pays on chart or super bill	1	2	3	4

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healthcare needs have a special set of attitudes, knowledge, interpersonal style, and communication skills. Parents define a positive attitude as showing empathy to the child and family and giving the family realistic reasons to be hopeful and optimistic. Knowledge is defined by expertise in diagnosis and current treatments. Interpersonal style refers to the time the physician takes with the family, not being rushed, and providing open-minded feedback to the child and families. Effective communication skills are defined as: being a good listener, listening to all symptoms before making a diagnosis, using familiar terminology or carefully defining new terms, and speaking to the child even if the child cannot respond verbally.

The effective physician also has a support staff that has been well trained to work with families and children with special healthcare needs. The support staff's style in working with the child and family should reflect the attitudes and values of the physician. Hence, greeting the family and the child, explaining the procedures that are to take place, and validating the patient's concerns about painful procedures should be a basic part of the examination. Finally, parents indicate that how the medical practice is organized is very important. Meeting family needs requires that the practice provide features such as: reasonable phone access to staff; consistent procedures in each examination; and streamlining procedures for paying the bill. The staff contribute significantly to helping the child and family through the many medical encounters that are a mainstay of the child and family's life.

The Survey (Table 1) can be a useful tool for parents and caregivers as well as physicians and staff. It provides a set of standards that parents and caretakers can use to evaluate the quality of care their children are receiving. Physicians

continued on page 80

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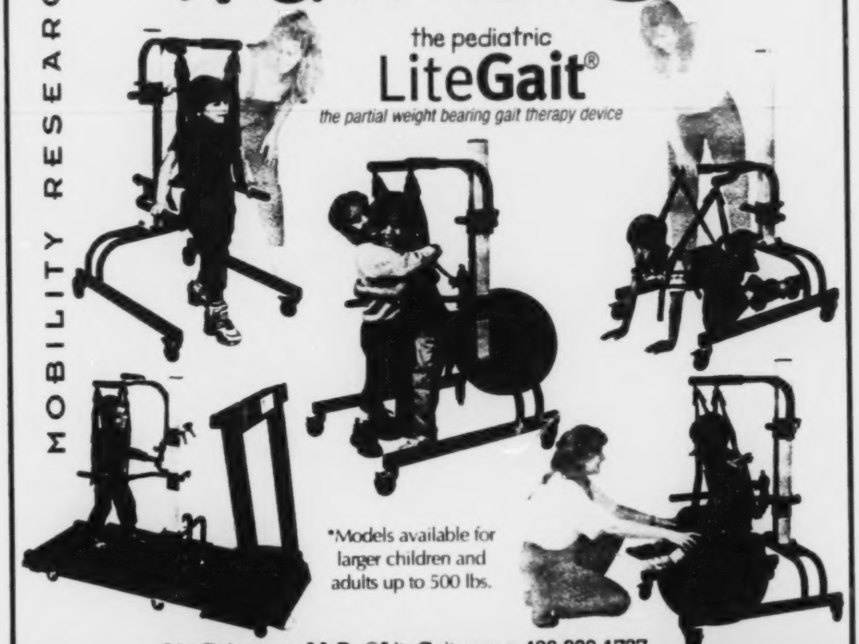

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continued from page 79

can use it to evaluate the quality of care they are providing to children with special healthcare needs. Physicians also can use the Survey as a guideline for staff training and office management. ■

Acknowledgement

We gratefully acknowledge the contributions of parents in the Improving Managed Care for Children with Chronic Health Care Needs Project. The study would not have been possible without the participation of Sharon Atwood, Elli Bogden, Lisa Carlson, Sherry Charlot, Janet Churchward, Brad Geeck, John Gooch, Velma Leftwich, Jackie Marchosky, Angela Moberg, Mae Moore, Sandra Partker, Aura Rubin, Bonnie Rubio, Leah Vincent, Darlene Watkins, Julie Webb, and Martha Young.

The *Improving Managed Care for Children with Chronic Health Care Needs by Including Parents as Participating Partners in the Medical Home* Project is supported by grant #041S17 from the Maternal and Child Health Bureau (Title V, Social Security Act), Health Resources and Services Administration, Department of Health and Human Services.

Tanis Bryan, PhD, and Karen Burstein, PhD, both special education faculty at Arizona State University, Tempe, are Co-principal investigators for the Medical Home Project Team.

Dr. Bryan brings extensive knowledge and experience in conducting community-based investigations to the team.

As a parent of a child with special healthcare needs and former CEO of a children's rehabilitation facility, Dr. Burstein brings expertise on the problems of families and children as well as research design to the team.

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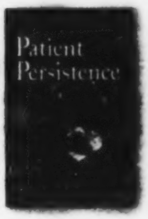

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INCONTINENCE:
Toilet Training a Child With Special Needs

by Claire C. Keeler, RN, CPNP

Parents often find that toilet training their child can be a frustrating process. Some children may toilet train quickly and easily, but for many children it can take time. If a child has special needs, it can be even more difficult. Parents know that every child is unique and different. Advice from other family members or friends may or may not be helpful.

Typically, children can achieve toilet training by 2 to 3 years of age, regardless of special needs. Toilet training increases a child's self-esteem and independence, especially as he or she enters school or daycare. It can also be a stressful situation. However, only you and your child can determine whether they are ready to learn.

Readiness Checklist

Your child's readiness to toilet train is related to his or her level of growth and development. The following items are organized according to motor, cognitive, and language development as well as toileting skills. Check the box next to the items that apply to your child. Some of the items in the list may not apply to your child. The more boxes checked the more likely your child is to begin toilet training.

MOTOR

- ☐ My child can sit with or without support.
- ☐ My child attempts to squat without losing his/her balance.
- ☐ My child is walking without help.
- ☐ My child is able to help dress and undress his/her self.

COGNITIVE

- ☐ My child searches for his/her toy.
- ☐ My child imitates me and/or others.
- ☐ My child plays make-believe.
- ☐ My child is able to sit down and play quietly for about five minutes.

LANGUAGE

- ☐ My child understands simple requests like, "Where is Mommy?"
- ☐ My child is able to show his/her needs using words, signs, or gestures.
- ☐ My child has a name for urine and bowel movements.
- ☐ My child tells me when his/her pants are wet or soiled.

TOILETING

- ☐ My child is able to stay dry for at least an hour.
- ☐ My child is aware of what a potty or toilet is for.
- ☐ My child is aware of being wet or soiled.
- ☐ My child's bowel movements are solid and well formed.
- ☐ My child is not currently experiencing a stressful situation like birth of a new sibling or changes in childcare arrangements.

Is your child ready to begin?

The Readiness Checklist, (left) can help you determine if your child is ready to begin the toilet training process.

There are several steps to follow to help clear the way:

- Have your child seen by your pediatrician for a medical check-up to make sure he or she is healthy before you determine readiness to potty train. Continence can depend on whether or not your child has a disease or disorder that affects the bowel or bladder.
- Also, be sure and let your nurse practitioner or doctor know if your child complains of pain when urinating, the urine has blood or pus in it, the urine smells foul or different, your child is always dribbling urine, or has a really hard time starting to urinate. These problems need to be addressed before toilet training begins or at any time in the process.
- Additionally, pain on urination or defecation can hinder the readiness process. The skin covered by a diaper can become red and irritated. This may cause pain when your child urinates, and may cause him or her to withhold urine. It is important to always keep the diaper area clean and dry so your child will not want to hold the urine.
- Often, children feel inhibited about having a bowel movement outside of a diaper. If they are pressured to have bowel move-

continued on page 84

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ments only in the toilet before they are ready, they may stop having bowel movements altogether. Likewise, if it hurts to have a bowel movement because of hard stools, your child is not going to want to pass it. This can lead to a vicious cycle. Slightly changing your child's diet may help, but check with your child's physician first. Fruits like pears, prunes, and peaches, which are high in fiber, can soften stools. Parents know which foods will work for their child.

Sometimes, medication is necessary for constipation to keep stools soft. Laxatives most commonly used are stool softeners like docusate sodium, osmotic laxatives like lactulose, and stimulants like Senokot® syrup. Other children may respond to suppositories or enemas. Again, it is important to always check with your nurse practitioner or pediatrician to see what medicine (if any) is appropriate.

Environmental factors

Begin training when your child is starting to learn cooperation, and when there is not a lot of stress at home. For instance, do not start toilet training around the holidays, when weaning him or her from a bottle, or soon after bringing home a new brother or sister. Also, from a practical point of view, it may be easier to start potty training when it is warm outside because your child will be wearing less clothing.

One of the first steps of toilet training includes keeping a diary for about three to five days. The diary should note when your child goes (either bowel movement or urine), when she or he is soiled, and what and when your child drinks. This will show you your child's toileting pattern and help clue you in as to when to have him or her start sitting on the potty.

Even if your child is fully trained, accidents often happen. Accidents may occur when your child is excited, fearful, absorbed in play, or awakened from a bad dream. They may also occur if there is any change in home routines, like the birth of a sibling, a move, or starting school. When your child is sick, expect accidents until he or she is better. However, if there are repeated, unexplained accidents, there is the possibility of an allergic reaction or an illness. In this case, you need to contact your nurse practitioner or doctor.

Your child is ready—now what?

After you and your child have determined that it is time to potty train, take him or her to the store and buy a potty. After choosing and buying the potty chair, start having him or her sit on the potty, clothes on, while you sit on the toilet. You can give your child a snack or read aloud to keep him or her sitting on the potty in order to establish a daily routine.

Then, during the next week or so, ask your child if it is all right to take his or her diaper off while on the potty. In the next

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couple of weeks, take your child to the potty after a bowel movement and place it in the potty. This lets him or her know that this is where the bowel movement belongs. Do not flush it in front of your child (for some children, it may be fun to watch it flushed, but others may be frightened and confused about where it went). Flush the bowel movement when your child loses interest and leaves the room.

If you meet with resistance to any of these steps, just back up and forget training for a couple of days. The next step is to offer to remind your child to go to the potty every hour. When he or she goes, leave it there and offer congratulations. Nighttime training should begin only when your child is dry during naps or dry for at least six hours.

Whatever system you decide to use, reward your child's successes with a lot of praise. It is important to be encouraging and positive. Occasionally, there will be accidents. The important thing is how you handle them. It is okay to show mild disappointment ,but never scold, punish, or make a really big deal out of it. Tell your child it is okay and he or she will go in the potty next time.

Tools for toilet training

There are many helpful techniques that may aid parents in the training process:

- "Role modeling" may allow your child to learn by imitation.
- Try an "open-door policy" in the bathroom so your child may see other family members using the toilet.
- Try placing a nonabsorbent cloth in your child's diaper so he or she can be aware of feeling wet.
- Small rewards may be given to encourage the child to sit on the potty longer or after they have successfully used the toilet. For instance, one parent put a basket on the top of the refrigerator full of inexpensive trinkets she had wrapped like tiny presents. Each time the child used the toilet she would give him a prize. You can help make the toilet-training process fun for both you and your child.
- There are many products availabe that can help with toilet training. There are also musical potties and potty charts with fun and colorful stickers. Another idea is to put a couple of drops of food coloring in the toilet bowl and have your child guess what the color of the water will change to after he or she urinates. Buy underwear with your child's favorite cartoon character. Make it a game where your child tries to keep the character from getting wet. Daytime wetting alarms (a sensor in the child's pants that signals when wet) may help the child notice when he or she is wet.

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Overcoming difficulties

The type of difficulty your child has with toilet training (bowel training, bladder training, or both) and the potential to achieve control depends on your child's special need and whether it is a physical or cognitive difficulty and the degree to which your child is affected. For some children, it may be difficult to reach the toilet and actually sit on it. Parents may have to help with positioning and keep their child in position while on the toilet. Other children have difficulties with communicating that they need to go, or parents have difficulty with communicating the ideas associated with toilet training.

There are some adaptations to the toilet area to help your child with a physical disability sit on the toilet. For older or taller children, there are raised seats along with safety rails to aid the child with positioning on the toilet. For toddlers, several brands of potty chairs have backs that can support a child leaning back. Positioning your child differently on the toilet seat may also help. Some experts have suggested that children straddle the toilet seat or potty chair. Seating the child sideways on the toilet may also be helpful. *(Specific toilet adaptations will be addressed in an upcoming issue.)*

RESOURCES

- **Steps to Independence**
  Bruce L. Baker and Alan J. Brightman
- **Keys to Toilet Training**
  Meg Zweiback, RN, CPNP, MPH
- **Potty Learning for Children Who Experience Delays** (video)
  S.R. Hays, MS, RN, CRRN

Books for Children:

- **Once Upon a Potty**
  Alona Frankel
- **The Potty Chronicles**
  Annie Reiner, LCSW

These items are available through the EP Library • (800) 535-1910

Communication

When communication is the problem, it may be easier on you to show your child where the bowel movement goes (in the potty) and allow him or her to watch you and other family members using the toilet. It may be necessary for children who have communication problems to work directly with a healthcare professional, such as a nurse or therapist, to help you with setting and achieving these goals. ■

Claire Keeler is a pediatric nurse practitioner who was a fellow at the University of Cincinnati University Affiliated Program. She conducted a study on toilet training children with special needs.

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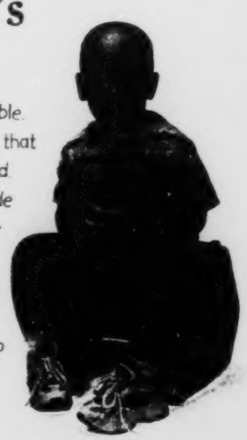

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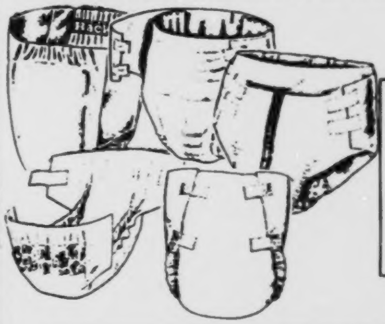

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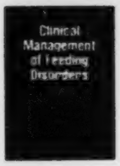

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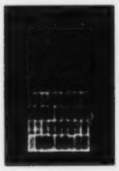

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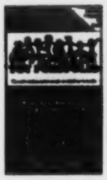

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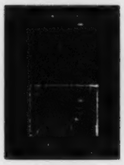

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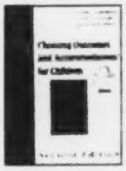

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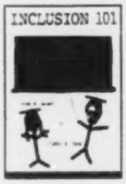

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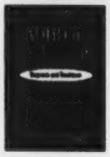

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Celebrate National Family Caregivers Month

The National Family Caregivers Association (NFCA) has declared November National Family Caregivers Month. The organization hopes to raise awareness and recognition for the 25 million family caregivers who provide care for a loved one with a chronic illness, disability, or who is elderly. In order to help celebrate National Family Caregivers Month, the NFCA asks that people "Share the Caring" and work with them to create activities and events that recognize the dedication of family caregivers. NFCA offers suggestions for programs, a media communication kit, educational materials, buttons, posters, tip sheets, background information, as well as education and support for family caregivers. For more information please call NFCA at (800) 896-3650; or go to their Web site: http://www.nfcacares.org.

CORRECTION:

The August issue contained incorrect contact information for the NFCA. The correct contact information is as follows:

NFC
10400 Connecticut Ave., #500,
Kensington, MD 20895-3944;
(800) 896-3650; Fax: (301) 942-2302;
E-mail: infor@nfcacares.org;
Web site: http://www.nfcacares.org.
We apologize for the error.

America Online Agrees to Offer Access to Users who are Blind

The National Federation of the Blind has dropped a lawsuit against America Online. The company has agreed to make its software compatible with programs to convert digital information to speech or Braille. The accord could open the Internet to thousands of people with visual impairments. The suit contended that the company was required by the Americans with Disabilities Act to provide equal access to users who are blind.

CALENDAR OF EVENTS

11/3-4 **Maap Conference** **(For families of more advanced individuals with autism, asperger syndrome, and pervasive developmental delay/not otherwise specified [PDD/NOS])**

"From Autism to Asperger's and Beyond: Continuing Our Journey"

Busch Gardens Holiday Inn Tampa, FL

This conference will be held in conjunction with the Center for Autism and Related Disorders, University of South Florida. Topics will include employment issues, positive behavioral supports, and friendships. For more information call (219) 662-1311; Web site: http://www.netnitco.net/users/chart/maap.html; E-mail: chart@netnitco.net.

11/3-4 **5th Annual Family Conference on Cerebral Palsy & Related Disabilities United Cerebral Palsy (UCP)**

Holiday Inn Wilsonville, OR

Topics will include feeding issues, independent living, assistive technology, job development, and legislative issues. For more information please call UCP Oregon at (800) 473-4581; or E-mail: htoliver@ucpaorwa.org.

11/3-8 **American College of Asthma, Allergy, & Immunology (ACAAI) Annual Meeting**

Washington State Convention &Trade Center and Sheraton Seattle Hotel &Towers, Seattle, WA

This conference will primarily be for professionals in this field. Topics that will be discussed include improving rhinitis and asthma, diagnosing obstructive sleep apnea, and potential therapies for the new millennium. For more information contact Diane Kubis at ACAAI: (847) 427-1200, or go to their Web site: http://www.acaaiplanner.com.

11/10-12 **World Congress and Exhibition on Disabilities**

Georgia International Convention Center Atlanta, GA

This conference will address issues faced by parents, caregivers, people with disabilities, educators, and healthcare professionals. There will be over 200 exhibitors including pharmaceutical, insurance, automotive, personal care, mobility, adaptive and augmentative communication, and much more.

For more information on the WCD call (877) 923-3976; (201) 226-1446; or go to their Web site: http://www.wcdexpo.com.

11/16-17 **American Speech-Language Hearing Association (ASHA) Annual Convention**

Honoring the Past—Shaping the Future • Washington D.C.

This conference, primarily for professionals will include many topics including speech and swallowing and the latest technology.

For more information contact ASHA at 10801 Rockville Pike, Rockville, MD 20852; automated phone (888) 321-2742; (800) 498-2071; TDD: (301) 571-0457; Web site: http://www.asha.org.

11/16-18 **National Perinatal Association (NPA) Annual Clinical Conference**

Evolution of Perinatal Health and Healing: Complementary Care & Non Traditional Practices

Hilton Charlotte and Towers Charlotte, NC

This conference, mainly for professions, will include workshops on trauma in pregnancy and the use of alternative and complementary medicine. For more information contact the NPA: (888) 971-3295; (813) 971-1008; E-mail: npa@nationalperinatal.org.

11/17-19 **Deaf Expo 2000**

Long Beach Convention Center Long Beach, CA

This consumer trade show is targeted at the Deaf and hard of hearing market. The exhibits feature merchandise and information on education, finance, health, publications, recreation, technology, and much more. For information write to Deaf Expo 2000 at 7712 Lankershim Blvd., North Hollywood, CA 91605-2815; or phone them at TDD: (877) 332-3397; Voice Relay: (888) 877-5379; or E-mail at DEAFEXPO@aol.com.

Justice Department offers phone assistance with ADA

The US Department of Justice offers assistance to the public on understanding the Americans with Disabilities Act through a toll-free telephone service. The service allows businesses and local governments to ask questions about general or specific ADA requirements and also provides information on how to file an ADA complaint. Specialists are available Monday through Friday, 10 am to 6 pm, except on Thursday, when hours are 1 pm to 6 pm. To use this service call (800) 541-0301 (voice), (800) 514-0383 (TDD); or Web site: http://www.usdoj.gov/crt/ ada/adahom1.htm.

Clinton orders hiring of more people with disabilities

At a ceremony celebrating the 10th anniversary of the ADA, President Clinton ordered federal agencies to hire 100,000 people with disabilities over the next five years. Clinton instructed all federal agencies to recruit people with disabilities for jobs at every level in the federal government, and establish procedures for accommodating their particular disabilities.

When speaking of Americans with disabilities, Clinton said, "They don't want excuses. Instead, they want opportunity in terms of jobs and careers."

Clinton also unveiled a new Web site that would provide people with disabilities and their families with information on a variety of topics. The new Web site, http://www.disability.org, contains information on employment, entrepreneurship, transportation, healthcare, education, and support services.

IRS allows new deduction

Responding to a request from Congressman George Miller, (D-7-CA), the Internal Revenue Service issued a ruling that will allow parents to deduct some of the costs associated with attending medical meetings related to their child's health condition. Professional and advocacy groups that focus on particular diseases of physical conditions frequently hold national meetings at which parents can meet with leading researches and health practitioners to learn about the latest techniques for addressing their children's healthcare. In many cases, parent do not have access to such state-of-the-art procedures in their communities and can inform their doctors the existence of new treatments discussed at these conferences.

This new ruling will enable parents, who often expend a great deal of money to learn about new treatments for their children to deducts some of the costs of attending the conference. For further information go the IRS Web site: http://www.irs.gov. Go to the Internal Revenue Bulletin 2000-19 (May 8, 2000 issue), Rev. Rul. 2000-24, pp. 963-964.

2001 S.W.A.T.s Up! CALENDAR

For the fifth year, model/actor/entrepreneur Daniel Ruiz is publishing the S.W.A.T.s Up! Calendar. Daniel, who has paraplegia, created S.W.A.Ts Up! (Standing With Attitude Today), in order to dispel negative stereotypes about the lives of individuals with physicl disabilities. The calendar features individuals 22 years of age and younger who have varying disabilities. Each subject is involved in sports, citizenship, leadership, and academics. The S.W.A.Ts Up! calendar is available for $10. The proceeds for 2001 Extreme Youth S.W.A.Ts Up! calendar will aid the Christopher Reeve Paralysis Foundation, as well as the Leisure Access Foundation, who will use the money to buy sports wheelchairs for children who do not have the money to obtain one on their own. To obtain a calendar call (786) 425-1967 or E-mail: cherlr25@aol.com.

SECOND ANNUAL HALLOWEEN CARNIVAL FOR CHILDREN WITH SPECIAL NEEDS

Phoenix Pediatrics, Ltd. of Phoenix, Arizona will be the host of a free, fun-filled Halloween Carnival for children with special needs. Phoenix Pediatrics and other contributors are sponsoring this event to allow children who are chronically ill and who have a disability to participate in this fun holiday. The carnival will be held Sunday October 29, 2000, from 1 pm to 4 pm at the Rawhide Pavilion in Scottsdale, Arizona. There will be food, games, prizes, balloons, face painting, and clowns, as well as special surprise entertainment. For more information on this event please call Bari Nemeth or Nichole Chavez at (602) 971-5121.

Photos by Jim Byrnes

Games and fun-filled activites will be part of the excitement agian this year at the Halloween Carnival.

VISIT OUR WEB SITE, WWW.EPARENT.COM, FOR UP-TO-DATE INFORMATION ON THE WORLD CONGRESS AND EXPOSITION ON DISABILITIES.

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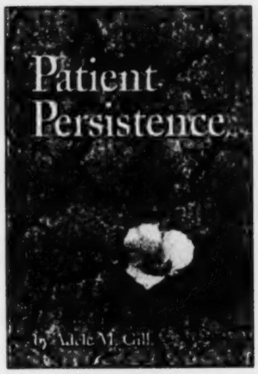
Patient Persistence

By Adele M. Gill and Friends
Exceptional Parent Press, 2000;
192 pages
Available through the
EP Library (800) 535-1910
Code: EP8004GN
Cost: $19.95 plus shipping
and handling (for orders received
before 11/30/00, the discounted
price for this book is $15.95.)



PATIENT PERSISTENCE celebrates the ability of people to overcome obstacles to achieve their goals. Author Adele Gill invited individuals from every background to tell their stories of "hope, courage, hard work, and endurance related to health, disability, relationships, family, ministry, career, accomplishment and challenge."

The book is divided into two sections: "Hope" and "Courage." Both sections contain selections that deal with the turning points in people's lives, when they found strength, hope, and the courage to persevere in the face of adversity. Many of the stories involve adults, but a few center around children.

Ms. Gill is a certified disability analyst/fellow with the American Board of Disability Analysts, and an advocate of inspirational/motivational self-help. She writes, "Patience and persistence are qualities that are vital to the discovery of our finest, God-given gift; the resilient 'Indelible Human Spirit.' These innate qualities propel people and enable them to do great things and overcome significant hurdles. For this, it is difficult to imagine any situation that does not require patience and persistence. Between the two exists a delicate balance. If you are patient, but not persistent, you may have the ability to wait for things to get better in your life, but not the determination to make it happen. If you are persistent but not patient, you may run the risk of not being able to wait for good things to happen in your life. In daily life, patience and persistence allows average people to accomplish great things."

Patient Persistence is both motivational and inspirational, offering help and hope to anyone who feels that his or her life is out of control, or that things have gotten so bad that there will never be a way to make it better. This book shows readers that there is always a way.

No Apologies For Ritalin

By Vidya Bhushan Gupta, MD
Exceptional Parent Press, 2000;
175 pages
Available through the EP Library:
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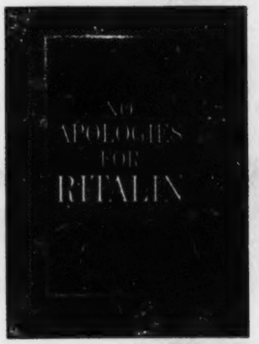
Cost: $21.95 plus shipping and
handling (for orders received
before 11/30/00, the discounted
price for this book is $16.95)



Despite its name, **NO APOLOGIES FOR RITALIN** is aimed at educating parents of children with ADD by opening the field to all the treatments available to treat the disorder.

The first half of the book is a look at what ADD is: the medical aspects, how it is diagnosed, and what causes it. Anecdotes of children diagnosed with the disorder and a discussion of how doctors arrive at their diagnoses begin the book. Issues that parents must deal with, such as understanding and coming to grips with the diagnosis of ADD, whether ADD is a product of bad parenting style, ADD's occurrence with other disorders, and who is most at risk, are discussed in this section as well.

Section 2 presents the pros and cons of all treatment options, both conventional and alternative, including non-drug therapies such as psychotherapy and behavior modification. The author, Vidya Bhushan Gupta, MD, MPH, FAAP, writes in his Foreword, "I have discussed the controversy surrounding the use of Ritalin and tried to dispel myths surrounding ADD and Ritalin: 'ADD is not a disease; it is simply a difference of temperament;' 'ADD is due to poor parenting;' 'Ritalin is a mind-altering drug like speed;' 'Don't give Ritalin to your children because they get hooked on it.'" He explains that his purpose for writing the book is so that "parents of children with ADD will not blame themselves for their child's predicament and will be able to use all the available treatments, including Ritalin, without guilt."

The book offers insights into other issues regarding ADD as well, including: who should treat the disorder and what the goals of that treatment should be; suggestions for parents on dealing with their child's ADD; whether children grow out of their ADD; and how to de-emphasize the negative labels of the disorder by recognizing and building on the strengths of children diagnosed with it.

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organizational spotlight

THE CYSTINOSIS FOUNDATION *The Cystinosis Foundation

The Cystinosis Foundation (CF) is an all-volunteer, nonprofit organization dedicated to providing services to anyone dealing with cystinosis. Via a multifaceted network of supports, including both local and national conferences, education/awareness activities, fund-raising for research, and other efforts, CF members have at their disposal numerous sources of assistance for improving the quality of life of their family member with this disorder.

What is cystinosis?

According to the National Organization for Rare Disorders (NORD), cystinosis is a rare, inherited disorder that affects both children and adults. It is a genetic disease that is characterized by the impaired transport of cystine, an amino acid, out of parts of cells. Cystinosis produces a build-up of cystine crystals in tissues throughout the body. This build-up causes the body's organs, especially the kidneys, to malfunction and, eventually, to fail. Different organs are affected at different ages.

It is estimated that 2,000 individuals worldwide have cystinosis, though exact numbers are difficult to obtain because the disease is often undiagnosed. With early detection and proper treatment, people with cystinosis can avoid serious health complications, such as kidney failure and neurological damage.

There are three types of cystinosis, which can appear at any age: infantile nephropathic (usually from 6-8 months after birth), late-onset nephropathic (usually between ages 12 and 13), and benign non-nephropathic (usually in adulthood).

Tackling the disease

While the ultimate goal of CF is to find a cure for cystinosis, its primary function is to support individuals and families seeking information. Among the range of services

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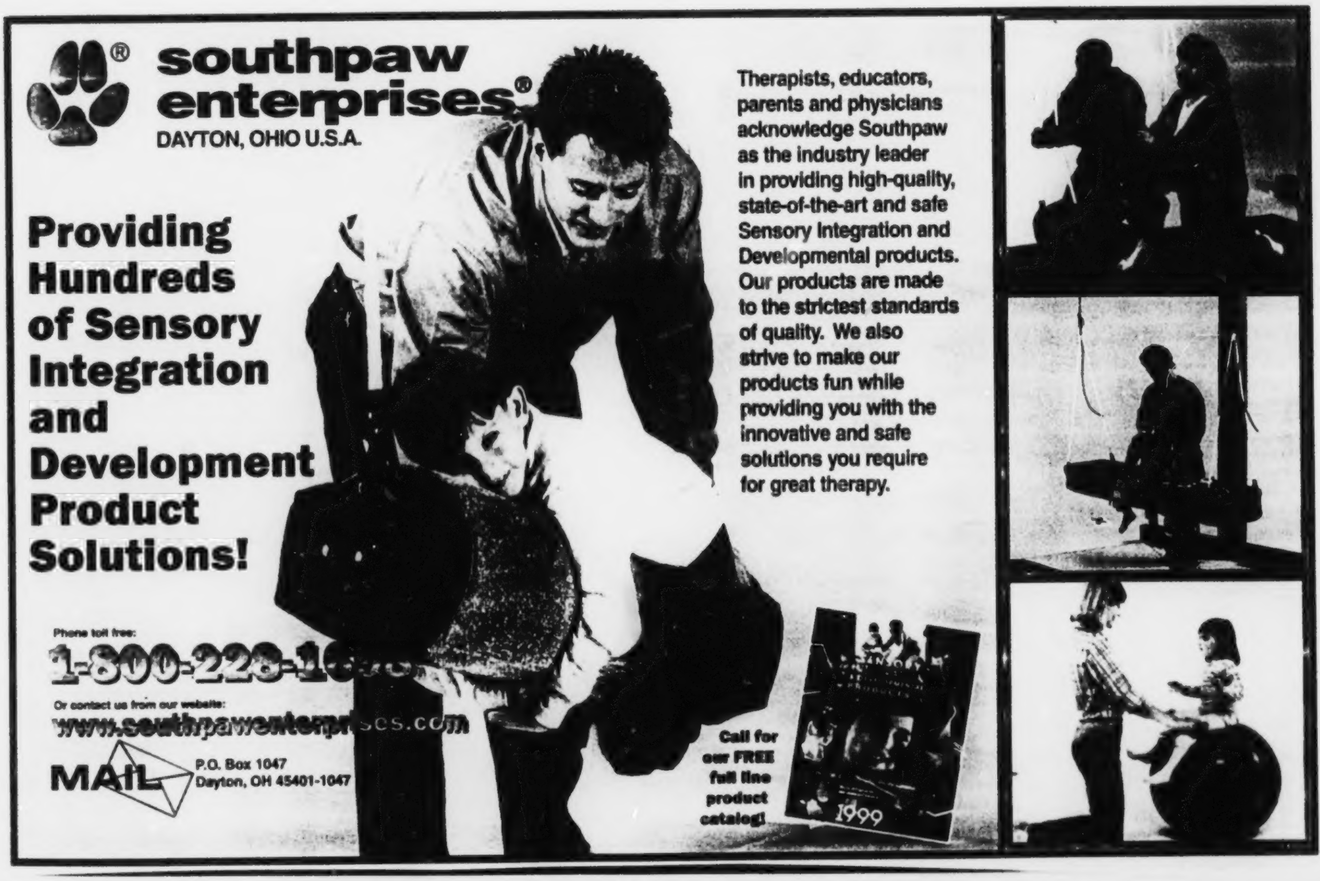

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offered by CF to its members (individual membership costs $20.00/year.) include:

- **Parental Support.** Member families are given information about cystinosis and advice on how to care for their family member with cystinosis. CF also refers families to other organizations and services that can help them and it publishes a member newsletters as well.
- **Education.** Through the distribution of literature, the general media, and receptions at medical meetings, CF works to educate the medical profession and the general public on cystinosis.
- **Research Support.** CF is active in raising funds to promote research on causes and treatments of cystinosis.
- **Affiliations.** As a member of NORD, a support and information organization for people with rare diseases, and the Alliance of Genetic Support Groups, CF is able to draw from other sources of assistance to benefit its members.
- **Conferences.** One of the many goals of CF conferences is to bring together people with cystinosis and their families to share their experiences living with this chronic illness. For parents, being able to interact with expert doctors and other professionals on cystinosis is also a major incentive to attend. CF plans to continue to broaden the availability of local conferences so that every family who has a member with cystinosis will be able to attend at least one, if not now then in the near future.

Early recognition and intervention

In infantile cystinosis, symptoms include excessive thirst and urination, failure to thrive, rickets, and episodes of dehydration. After one year, these children normally experience crystals in the eyes. Early recognition and treatment of cystinosis can help avoid complications.

CF is ever mindful of the difficult work to be done in its pursuit of a cure for cystinosis. Some of the current achievements in medical research include:

- carriers of cystinosis can now be detected;
- the gene for cystinosis has been isolated;
- as a result of studies, new medications have been approved by the FDA and others are being studied. ■

Upcoming conference

The annual national Cystinosis Conference will be held in New Orleans on November 3,, 4, and 5, 2000. The conference will feature the research of Dr. Jess Thoene, who is Professor and Chair of the Human Genetics Program, Hayward Genetics Center, School of Medicine, Tulane University.

Contact the Cystinosis Foundation at: 2516 Stockbridge Drive, Oakland, CA 94611; Phone: (800) 392-8458; Web site: http://www.cystinosisfoundation.org.

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First, I Want To Be A Mom

by Denise Sherer Jacobson

Our Role Model for October is Denise Sherer Jacobson. Denise and her husband Neil refused to allow a disability stop them from fulfilling their dream of parenthood. Both Denise and Neil have cerebral palsy and were not encouraged to pursue a "family life" when they were growing up. Denise, a writer, has shared with EP the story of how her own role models helped her keep her dream of motherhood alive.

Three pairs of sneaker-clad feet tramp up the wooden porch steps. I open the front door and quickly press the joystick of my wheelchair in reverse to make way for the three seventh-graders: my son David and his two friends, Adam and Rashad. As usual, they file in, mumble their routine hellos, and deposit their heavy backpacks.

"How did it go today, guys?" I ask from my out of the way spot. They each give me one-word answers, "good," "okay," "fine." I follow with, "Any homework?"

"No," they respond in unison.

"There are snacks in the fridge," I tell them, and they trudge off to raid the pudding cups in my refrigerator. Then they head for the basketball hoop in the backyard. I hope they close the back door after them.

Proud parents Neil (left) and Denise with their son David.

Seeing past limitations

As most girls do at one point or another, I dreamed of being a mother someday. I could picture scenes where my child would come home from school with friends, have their snacks, then run and play. But I didn't share my fantasies; I was afraid people would say I was being unrealistic. After all, I had cerebral palsy. I had spent my childhood through my late teens hobbling laboriously around on crutches. I would feed and dress myself in a great deal less than lightening speed, and I knew I would probably never be employed as a radio talk-show host because of my difficulty in speaking.

"How would you ever be able to take care of a baby?" I feared the cross-examination and teasing from family and friends. I couldn't offer any tangible proof or practical answers. All I had was a gut feeling that I could do it, and the words my mother had drummed into my head to encourage me through my most frustrating efforts when I was a child: "Where there's a will, there's a way."

I knew that parents with disabilities existed. Mrs. Kirinsky, my OT in elementary school, was married and had a 4-year-old daughter. Both Mrs. Kirinsky and her husband had cerebral palsy. I remember my therapist's round face and short-cropped, reddish-blond hair. I also remembered she had a scissored gait because she wore long-legged braces. She curled and uncurled her fingers with robotic dexterity. I often wondered how Mrs. Kirinsky had diapered her daughter when she was a baby, but I was too shy to ask such a personal question.

There was also Shelley Koy, a camp counselor I had known through my teens and twenties. His parents both had post-polio—their mobility and movements significantly encumbered by their disability. How on earth did they manage raising him and his younger brother, J.J.? I didn't even know how to bring up the subject. I wasn't used to talking about such things.

The possibility of having my own family was not really discussed during my growing-up years. I played with the babies as they sat in their carriages and—to more than one mother's surprise—rocked even the most fussy baby to sleep. But, every now and then, I would overhear adults make assumptions of the future: my nondisabled sister and her peers would "marry and have kids," while I would "go to college and have a career." (In those days the two were mutually exclusive). The underlying message was not lost on me and I ached to prove that my life would be much more than what everyone expected it to be. I also felt the enormity of the burden in that, unlike the rest of my peers, I had to prove anything at all. Perhaps that's why I held on so tenaciously over the years to my memories of Mrs. Kirinsky, Shelley

continued on page 101

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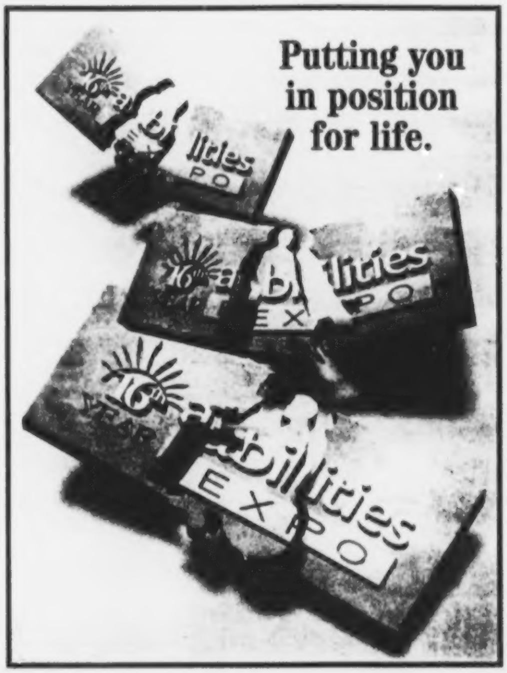

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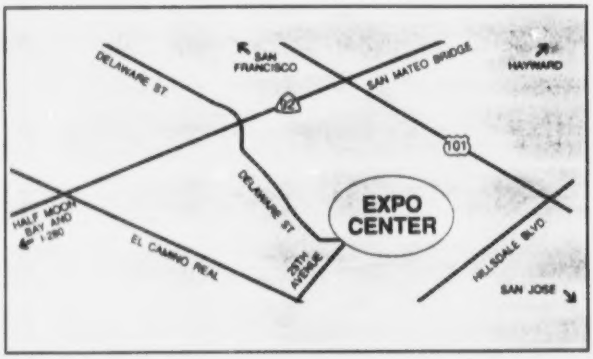
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Koy's parents, and my mother's indelible words. That was all I had until I met Neil.

Sharing a dream

The first time Neil and I discussed the topics of children and adoption was on our first dinner date, more than 17 years ago. Since our paths had crossed frequently in New York when we were young, we didn't need to warm up with small talk. Instead, I listened to Neil talk about growing up with his parents, who were Holocaust survivors, spoke little English, and were frightened by a medical profession that had a very pessimistic view of children with cerebral palsy.

Both my parents and Neil's had high expectations for us to be self-sufficient—physically and financially, and, indeed, encouraged us to achieve our maximum potential.

"When I was 5, a doctor recommended my parents put me in an institution," he explained as he slouched casually in his wheelchair. "He thought that it would be too much of a strain on them to raise me because of their past. So, I went with my father to see the institution." He shook his head. "It was horrible. My parents were so afraid that I might be taken away, my mom took all three of us kids to live with relatives in Florida for a year. But when I saw those kids…" Neil's voice trailed off for a moment. "Ever since then, I've wanted to adopt a disabled child."

"Don't you think it would be hard rais-

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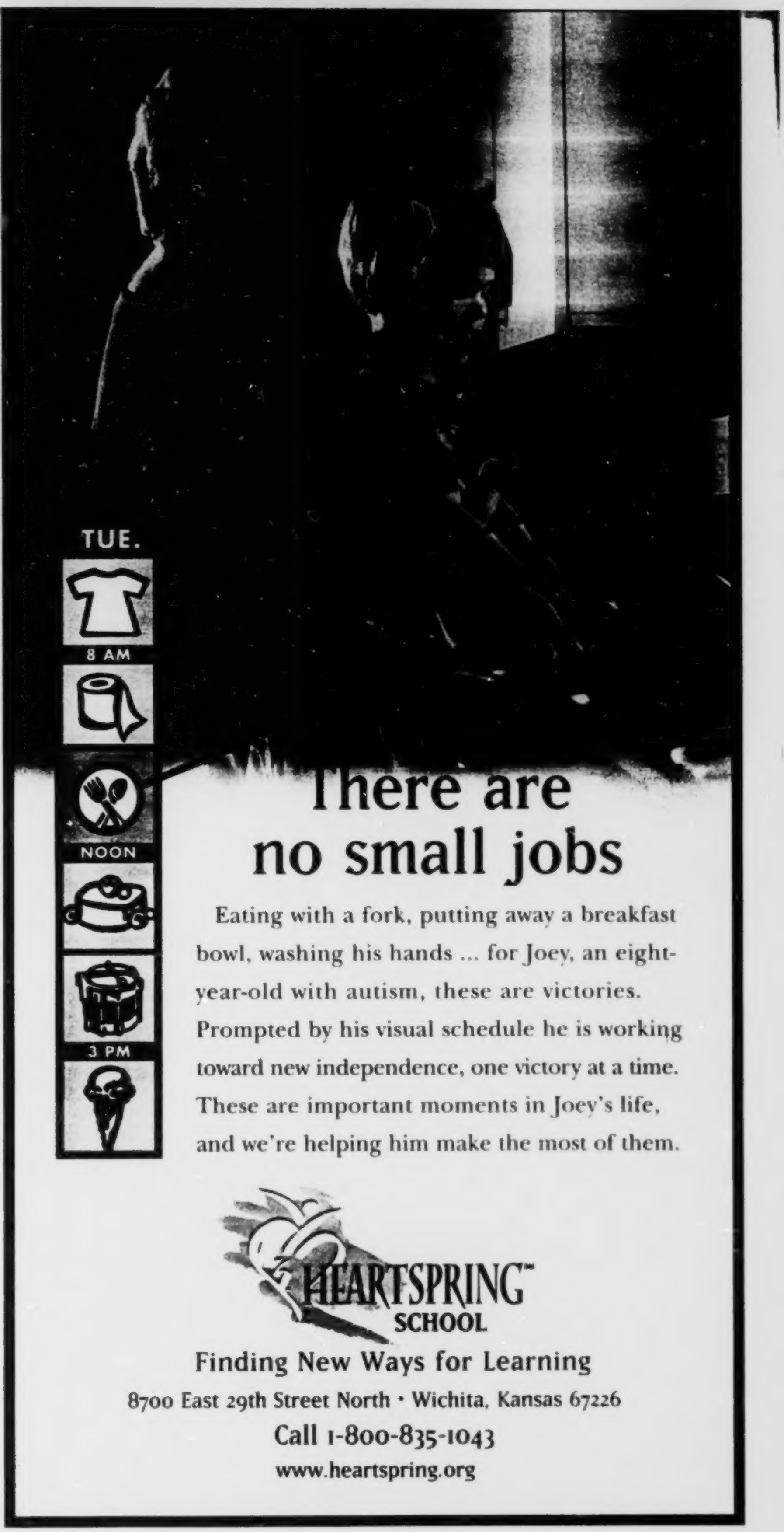

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By that time, I was 36, a bit set in my ways, and not sure I wanted to take on the never-ending responsibility of motherhood.

ing a disabled kid? Having to relive some of the same things you went through as a child?" I asked.

"But *I* survived!" he answered with undaunted enthusiasm. "I'd make a great role model."

I didn't know about being a role model—first, I wanted to be a mom. "I've never given a lot of thought to adoption," I said, tightly clasping my hands under the table before admitting, "I've always wanted to have a baby."

"Oh, so would I!" Neil's whole face brightened. "That would be such a kick!"

I'm sure that if our parents had been flies on the wall during that conversation, they would have dropped into our soup! Both my parents and Neil's had high expectations for us to be self-sufficient—physically and financially, and, indeed, encouraged us to achieve our maximum potential. But they rarely ever spoke to us about what that independent life would include. Perhaps they wanted to protect us from the disappointments they foresaw as we entered adulthood, trying not to give us false hopes about falling in love, sex, and marriage. I'm sure, too, that our total independence was a difficult adjustment for them since they had physically parented us many years longer than they parented our nondisabled siblings. Although they were able to see success in our futures, I doubt if parenthood was a choice they had expected us to make.

Dreams become reality

The conversation Neil and I had that evening was the first of many we had over the next four years. Finally, we received the phone call regarding a 6-week-old baby boy, who was "at risk" for cerebral palsy and who needed a home. By that time, I was 36, a bit set in my ways, and not sure I wanted to take on the never-ending responsibility of motherhood. Neil and I had been married for several years and we had a comfortable life. Neil worked as a systems analyst and I wrote and consulted on disability issues. I had also lost touch with the gut feeling I had had about being capable, emotionally and physically, of motherhood. Fortunately, Neil insisted we check it out. So how could I refuse?

As soon as I held David for the first time and his eyes locked onto mine, I knew he was my son. It turned out he did not have cerebral palsy (he has minimal attention deficit disorder and language processing issues). That was over 13 years ago. There were challenging times during those years. I have struggled through 40-minute diaper changes when help didn't show up on time. I have fought off paramedics who tried to separate me from my 4-year-old son, determined to whisk him off to the hospital because they panicked over a nasty, though non-life-threatening, gash on his finger. I have ridden out the tide of tantrums over bedtimes, video games, and overdue book reports. And the teen years are just beginning!

Like all families, we will keep having our ups and downs, but I no longer have reservations about declaring I'd make a good mother. The proof is in my backyard. ■

Denise Sherer Jacobson is an interviewer/editor for the Disability Rights and Independent Living Movement Project at the University of California. She wrote a book, "The Question of David," about her and Neil's experiences with the adoption and parenting of their son, David. Denise and her family live in the San Francisco Bay area of California.

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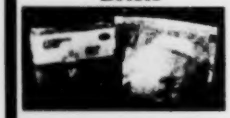

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Achieving Freedom and Independence with Vantage Mobility International

EP recognizes corporations that support the disability community, provide employment opportunities for and feature people with disabilities in their advertisements.

Imagine having your greatest dream—receiving a much-needed gift you cannot afford—come true. Penny Strickland of Wilmer, Alabama, dreamed of a full-size, easily accessible van to make life a bit easier for herself, her husband, Shannon, and her three daughters: Lauren and Leann, both 7, and Payton, 12.

Earlier this year, Strickland's brother, Wes Thomas, wrote a letter to the "Live with Regis & Kathie Lee" television show nominating her for a special award. Parts of his letter read, "If the Mother of The Year Award is given out to everyday people, the best candidate would be my sister. She is the mother of three very special girls.....Payton, Lauren and Leann all have cerebral palsy.....My sister makes many sacrifices for her girls.....and what little time she has to herself is spent as a parent consultant for children's rehabilitation services. I can think of no one more deserving."

The producers of the show teamed up with Vantage Mobility International (VMI) and Ford Mobility Motoring to make Strickland's dream come true. She was presented with a full size Ford Econoline Chateau van, which was donated by Ford, and a conversion donated by VMI.

Strickland finds her new gift to be user friendly and a vast improvement in enabling her to get her daughters to school, doctors' appointments, and everywhere else they need to be.

Behind the scenes

VMI was founded in 1988 as Vantage Mini Vans. It began with two partners who were disenchanted with the lack of customer service at a Phoenix-based van conversion company. "We try to develop products that will deliver high customer satisfaction," says Doug Eaton, Vice President of Sales and Marketing. "We look at our business through the eyes of our customer. At VMI, we think along these lines: If I used a wheelchair, what would I want?"

Today, VMI is the only manufacturer that routinely surveys their customers. VMI attempts to call every customer within two months of purchasing a converted van. "Our CSI (Customer Satisfaction Index) gives us a benchmark on how we're delivering on what we promised," Doug Eaton says.

John Brain is a customer whose 11-year-old son Terry has cerebral palsy. Brain bought a VMI Ford Windstar minivan with a Summit conversion (one of three available conversion options) in January. Terry has limited physical capabilities and uses a wheelchair to get around. Previously, Brain had been transporting his son in a truck, but now cannot imagine living without their converted van. "It used to take 10 to 15 minutes to get him in and out of the truck, and either my wife or I had to stay home when we had

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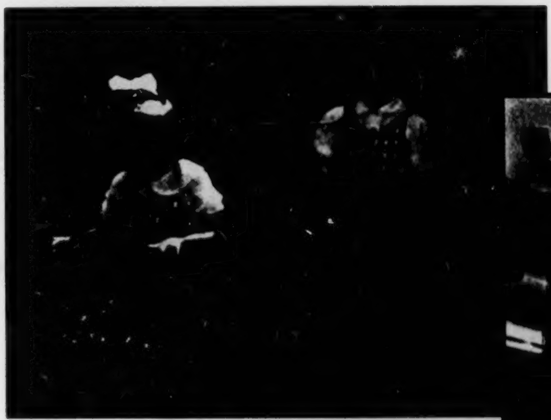
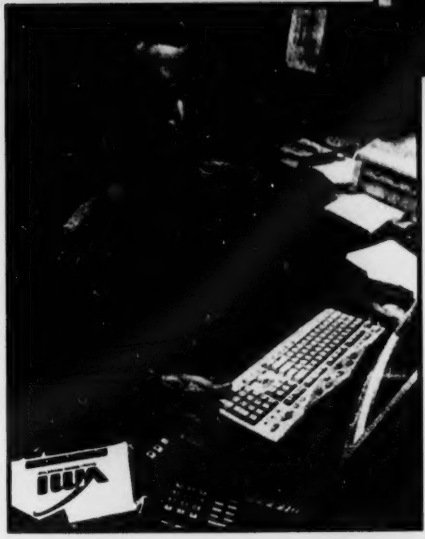


Photo by Ralph Freso

Above left: Penny Strickland with her daughters in their conversion van. Above right: The Brain family. Left: Todd Witte, a customer service representative at VMI.



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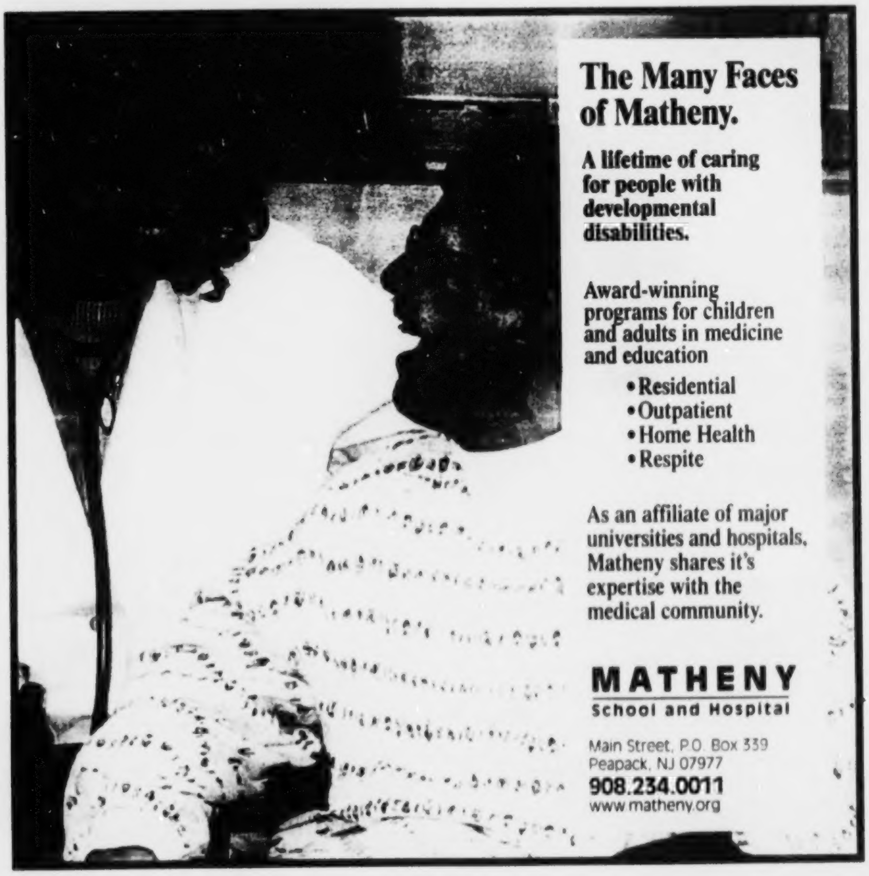
Corporate Citizenship

Besides being a company that prides itself on innovation, safety, dependability, and customer satisfaction, VMI is known for its community support of a variety of charities as well. Some of their charitable activities include:

- Closing their plant early once a year and staging a carnival for their own employees, offering food, games, and raffles, of which all the proceeds go directly to their local Muscular Dystrophy Association (MDA) charity. The carnival takes place during the national MDA telethon, and VMI employees also donate an hour of their time answering phones. Company management also donates money directly to the charity.
- Supporting the Arizona Spinal Cord Injury Association, which includes either a donation or providing food for a fund-raising event.
- Taking part in their local multiple sclerosis (MS) Walk.
- Providing sponsorship to the KIEV Christmas Party for Special Children and providing 3,000 children from the Leukemia Society, National Childhood Cancer Foundation, orthopaedic hospitals, rehabilitation centers, and similar facilities in Southern California with a fun experience with Santa, celebrities, food, and gifts.
- Supporting the Spirit of ADA Torch Relay, among other ADA 10th anniversary celebrations.



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continued from page 104

places to go. The ramp has made it much easier for Terry to get in and out. He sits like a little king in the back." He adds, "The sales rep did a super job informing us of the things we needed to know. I called around to a lot of other places and they would just answer the questions asked."

VMI Executive Assistant Serena Garriss explains that the wide range of options available in conversions allows VMI to be attuned to each customer's individual needs. "We have a list of options people can receive and if they have a special need, we're not going to tell them 'no.' We're going to figure out a way to do it for them."

A simple peace of mind

Safety, reliability, and style are hallmarks of VMI International. The three minivan conversions VMI offers—Northstar, Summit, and Trekker—reflect that commitment.

Kay, Denny, and Matthew Ciganovic from Charlotte, South Carolina, have found freedom in their Dodge Caravan with a Summit conversion. Matthew, 12, has Duchenne muscular dystrophy and he cannot bear any weight on his legs. "We have always been really mobile and love to travel. The minivan just gives us so much—we do everything in the car," Kay Ciganovic says. "Matthew has even had to lie down in the back and been quite comfortable. I feel like we could drive cross-country and camp in this van. It's keeping us mobile."

The Northstar conversion minivan comes equipped with an in-the-floor ramp that glides out silently as the vehicle kneels and the door slides open, all by VMI's "One Touch" remote operation.

According to Doug Eaton, "With its unobtrusive doorway, our Northstar has the most user-friendly approach of any vehicle in the market. It gives peace of mind and a psychological edge having the ramp stowed away, versus having the ramp block the doorway. Our market research has also indicated that the slide-out ramp is preferred within the physically challenged community."

Another VMI innovation is the Power Kneel™ system. David Eaton, Vice President of Quality Assurance, explains: "The Power Kneel™ is a mechanical device that pulls the vehicle down when the door opens and the

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ramp comes out. It pulls the ramp out so the ramp angle is less steep, and it allows people to get up and down the ramp easier."

Todd Witte, a customer service representative for VMI, owns a Chrysler Town and Country minivan with the Northstar conversion. Witte has multiple sclerosis and needed the van conversion because it was becoming too difficult to use his scooter lift on the back of his truck. "The Northstar conversion makes VMI unique because there's no ramp inside the doorway," he says. "You have a clear, open van just like a regular, unconverted van."

Witte has been working with VMI for five years now. He just purchased his Northstar converted van last November. "The service that we offer gives people who are physically-challenged a window to the world," Witte says. "The two most important things in my life are my van and my wheelchair. Without my van and wheelchair where would I be? Sitting in the corner."

As a customer service representative, Witte answers Phoenix-based VMI customers' questions and provides technical support. "I can help our customers out because I understand what a lot of their problems are, and a 'normal' person doesn't know. I can sympathize with our customers and go that extra little distance just because I know." He adds, "My van gives me a chance to go to work and be an asset to society."

Innovation and safety

David Eaton explains that in a VMI vehicle, customers can feel safe. "All of the conversions that we produce are fully crash tested to meet Federal Motor Vehicle Safety Standards (FMVSS)," he says. "They involve extensive tests like fuel system integrity and occupant crash protection." Their high safety standards and innovation allows VMI to stand behind their vehicles 100 percent.

Customers definitely believe that safety matters. "The reason we went with VMI is because they crash test the vans and that was really important to me. You don't want a van that isn't going to structurally hold up in an accident," says Penny Larson, a single mother of a son with cerebral palsy. Larson owns a Dodge Grand Caravan.

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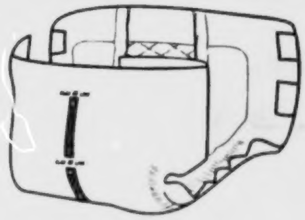

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continued from page 107

The recipient of the donated van, Penny Strickland, was also concerned with safety while transporting her daughters in their wheelchairs. She was impressed with the EZ Lock system, which enables the wheelchair users to be locked down quickly with the push of a button.

Making the connection

While VMI manufactures the converted vans, their dealer network truly makes it happen for the customer. There are more than 150 VMI dealers in 45 states and seven foreign countries who make the vans available to customers, add adaptive equipment, and service the vehicles. "The heart and soul of our business is our distribution system. We're very particular about who we select. Most important, they have to emphasize customer service," Doug Eaton says. "They have to be outgoing in their sales effort, they have to stock at minimum one van (although many of our dealers stock as many as 15 vans), they have to attend our service school and represent us with fairness and consistency and in an ethical manner to the physically challenged community."

All dealers must attend VMI University, a technical service training school. There they are taught the intricacies of the vehicles and learn how to fix them properly.

According to Garriss, VMI works with their dealers to ensure that customers' special needs are fulfilled. "We look for dealers who are going to be accommodating to their customers." VMI also requires their dealers to be recertified every two years.

The dealers also help customers finance the vans according to their needs. The vans and their conversions can be financed either separately or together through traditional lending sources for up to 10 years. For customers who may be eligible for insurance funds, insurance settlements, Veteran's Administration funding, vocational rehabilitation funding, state funding or worker's compensation, VMI dealers work to simplify the red tape. Says Garriss, "If a customer goes to a dealer and says, 'I'm applying to have a conversion paid for on my van,' the dealer will help them determine their eligibility and assist in filling out the necessary paperwork." Garriss adds that because VMI has state and federal "qualified vendor" status, its dealers qualify to receive payment from state and federal agencies that provide funding for van conversions.

Larson utilized state aid to convert her van. "We had no transportation and I wasn't going to spend money on a car when Jason is so big and only getting bigger. The state paid for modifications and I paid for the van. It took a year and a half from the time I asked until we got the van because of the state funding, but it was worth waiting for."

The van conversions take approximately six to eight weeks to be completed. For customers who want immediate results, the VMI Priority Delivery Network allows them to choose from 60 to 100 vehicles that have already been converted. Customers will receive these vehicles within one to two weeks.

With various types of financial assistance it can be a reality to almost everyone. "We're giving our customers an independence they've never had before," says Michele Heffernan, Marketing Coordinator at VMI. And independence is what VMI is all about. ■

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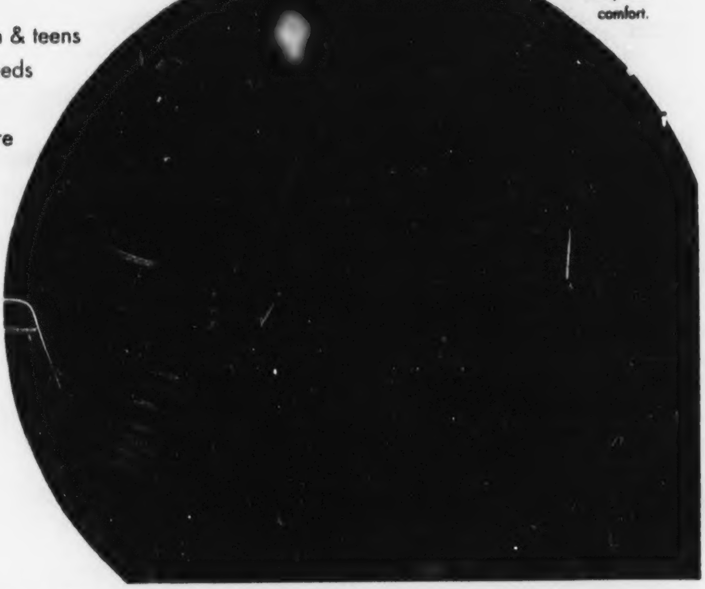

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familiar faces

CILENTO FAMILY

A happy family! From left to right, **Joseph Cilento**, holding **Stephanie**, 6; next to them are **Joseph Jr.**, 4, **Anoula**, 6 months, and **Dimitra**. Stephanie has severe quadriplegic cerebral palsy with a seizure disorder. She experienced oxygen deprivation at birth. Stephanie attends United Cerebral Palsy of Nassau. Her favorite activities are bird watching with her grandfather and listening to music. She and her family live in Long Island, NY.

OLIVER & ALEX

Oliver Huston, 2, and his big brother **Alex**, 5, are enjoying the sunshine! Oliver has spinal muscular atrophy and uses a power wheelchair. He is tube fed and attends occupational and physical therapy every week. Oliver loves chasing Alex in his power chair. He also enjoys the swings at the park, swimming, and visiting his grandparents. The brothers' mom and dad, Lance and Lisa, say that their sons are very happy little boys who love playing together. The family live in Apple Valley, MN.

PAYTON

Payton Ashley Mabry, 6 months, is ready to hit the road. Payton has Down syndrome and underwent open-heart surgery at 2 1/2 months of age. She enjoys playing with Tigger and Pooh bear, and, as the picture testifies, she loves driving her car. Her mom, Heather, says that Payton is "the sweetest child to be around." Payton lives with her mom and dad, Ken, in Dallas, GA.

Would you like to share a favorite candid snapshot or slide of your child and/or family with other readers of EXCEPTIONAL PARENT? Send it to: Readers' Photos, *EXCEPTIONAL PARENT*, 555 Kinderkamack Road, Oradell, NJ 07649-1517. (Please do not send originals or "one-of-a-kinds" as we regret that **photos cannot be**

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ANGELO

Say cheese! **Angelo Edward Camino-Chavira,** 3, poses for his school picture at Encanto Head Start, where he is mainstreamed with an aide. Angelo has cerebral palsy and can walk independently with forearm crutches for short distances. He currently receives adapted physical education, and speech, occupational, and physical therapies. Angelo enjoys riding his adapted tricycle, playing soccer, and reciting the "Pledge of Allegiance." He lives with his mom, Jennifer, and dad, Edward, in San Diego, CA.

CULVER

What's up, doc? **Culver Stan Meadows-Gall,** 18 months, looks very"hoppy!" Culver was born with Down syndrome and recently underwent open-heart surgery to correct a ventricular septal defect and mitral valve regurgitation. His mom, Laura, says he is doing fine and has more energy than ever. He receives both occupational and physical therapies. Culver loves music and people. He lives with his mom, dad, Clemens, and sister, Rhiannon, 4, in New Haven, CT.

ALYSSA

According to her mom, Deborah, **Alyssa Truncale,** 3, is as sweet as her smile! Alyssa was born with bilateral craniosynostosis and currently has an undiagnosed syndrome. She has both developmental and physical delays. Alyssa loves Teletubbies, music, mealtimes, and getting hugs and kisses from her family. Alyssa lives with her mom, dad, Robert, sister, Amanda, 14, and brother, Nathaniel, 8, in Mechanicsville, MD.

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returned.) On a separate sheet of paper, write your child's full name, age at the time the photo was taken, address and daytime phone number. Please identify everyone in the photo. If you like, you can also write a few sentences about your child. Then look for a familiar face in an upcoming issue!

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new products

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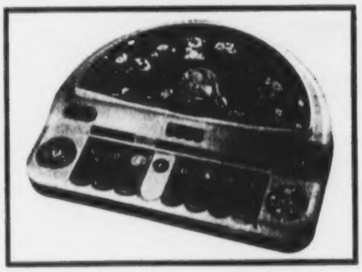

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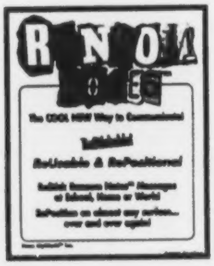
KIDdesigns, Inc., 1299 Main St., Rahway, NJ 07065-0902; Phone: (888) TOP-TOYS (867-8697); Web site: http://www.kiddirect.com



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The ABLEDATA database of assistive technology and rehabilitation equipment contains information on more than 25,000 products for persons of all ages who have a physical, cognitive, or sensory disability. Products are chosen for this page by the ABLEDATA staff based on their specific applicability to or design for children who have disabilities. ABLEDATA, operated by Macro International Inc., is funded by the National Institute on Disability and Rehabilitation Research under contract number HN-96015001.

For more information on these and other assistive devices, or to submit product information for the database (and possible inclusion on this page), contact: **ABLEDATA, 8401 Colesville Rd., Ste. 200, Silver Spring, MD 20910; (800) 227-0216 or (301) 608-8998 (voice); (301) 608-8912 (TTY); (301) 608-8958 (fax); Web site: http://www.abledata.com.**

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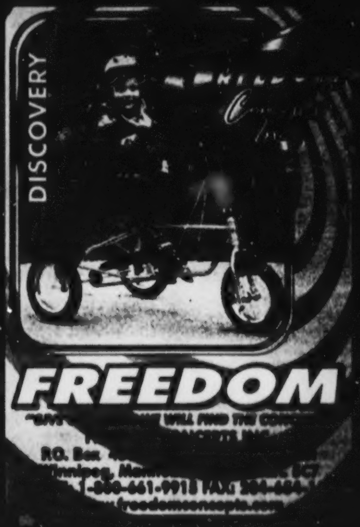

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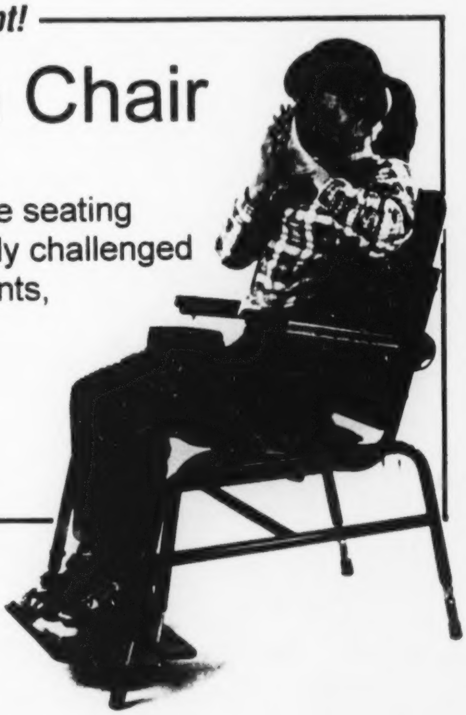

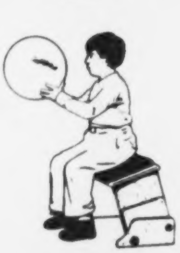

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One Great Kid!

by Anna Prendella

Trick-or-treating sisters! (From left to right): Katie Jo is Queen Amidala, Lee is dressed up as a soccer player, Tatiana is Barney, and Anna disguises herself as a set of teeth.

Some people don't understand my 14-year-old sister Lee, who has Down syndrome. They think she's weird. Their first reaction to her is, "What's the matter with her?" I know this, even if they don't say it aloud.

Many people think Lee should go to a different, special school. My parents don't think that way, so she goes to the same school as I do. No plan is perfect, though. Some children at school are downright nasty to Lee. On the school bus, kids will pretend to be her friend and then laugh behind her back. When my friends and I try to stop them from being so cruel, they say, "Mind your own business!" But that IS my business—Lee is my sister. She is human and has feelings, too.

There are good things about Lee going to school with me. Almost every girl in her grade is her friend. I have seen her in school sometimes laughing together with them. They invite her to parties, talk to her, play basketball with her, and make sure she is always included in everything. Lee is even a member of the school basketball team. When we pick her up, she is usually talking merrily with her friends and absolutely refuses to get in the car. "I'm having too much fun," she protests.

Lee has a knack for being likeable. She is friendly, outgoing, and just has something about her that makes you like her when you first meet her. At the public pool, she will always be in the middle of things, laughing and talking with the crowd. At her special camp, all the counselors and campers are always patting her on the back, playing, and talking with her. They say to us, "That Lee of yours, she's one great kid!" People even walk up to my mom when she's out and ask, "How is your daughter Lee?" It makes everyone in our family feel good to know that there will always be people watching out for my sister in this unfair world.

I like Lee the way she is, and I'm glad she isn't just like everyone else. To me, Lee is better than any kind of older sister. Lee can't take care of herself. She can't cook and needs help in the bath. Still, she is kind; Lee is almost always the first one to comfort me when I'm upset. She is understanding and is sympathetic whenever I'm sick. And I don't care what other people think. I know that Lee and people like her are very special. ■

Anna, 11, and Lee live with their parents and two other sisters, Katie Jo, 7, and Tatiana, 3, in Bernardsville, NJ. Anna and Lee are attending an after-school basketball camp this fall at their local YMCA for children with disabilities and their siblings.

MOM & DAD'S TURN

Anna's mother, Roseanne Mirabella, and father, J. Michael Prendergast, speak proudly of the close relationship shared by their two eldest daughters. "At a very young age, Anna was able to understand the special needs of Lee. She has often taken it upon herself to assist Lee in activities or in completion of tasks, and she is always there with a pat, a hug, or a smile when Lee is successful. She is very proud of her sister and one of her biggest cheerleaders at sporting events. Last year, Anna made signs saying 'Let's Go Lee!' to cheer her big sister on to victory at Lee's basketball games. Anna and Lee have developed a special bond between them and quietly share in each other's joys and sorrows."

The Children's Page welcomes contributions from children who have disabilities, their siblings, and their friends. Be creative! Send your stories, photos and/or artwork to: Children's Page, EXCEPTIONAL PARENT, 555 Kinderkamack Road, Oradell, NJ 07649-1517. Be sure to include your name, address, and daytime telephone number! Now on the Web! We will now be including **Familiar Faces** and **Children's Page** on our Web site, www.eparent.com. Please send us your photographs with the understanding that doing so gives Exceptional Parent permission to put the photos on the Exceptional Parent Web site, exactly as they appear in the magazine and with the same text.

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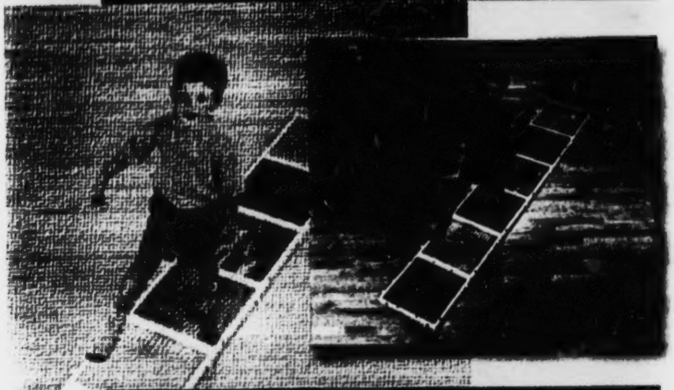

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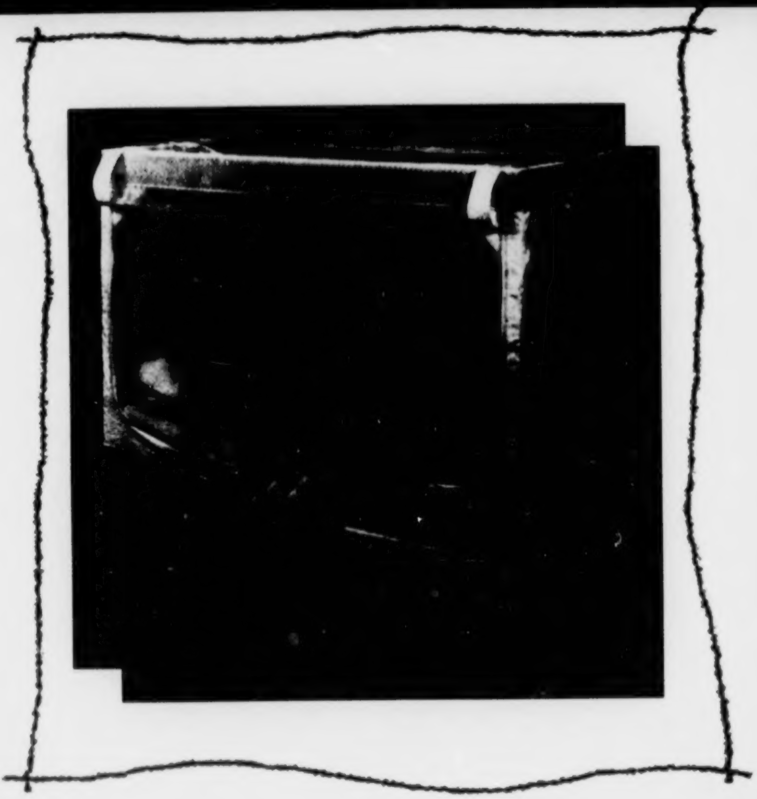

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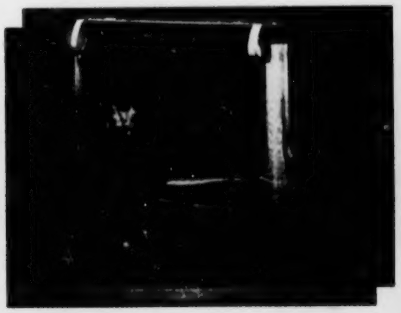

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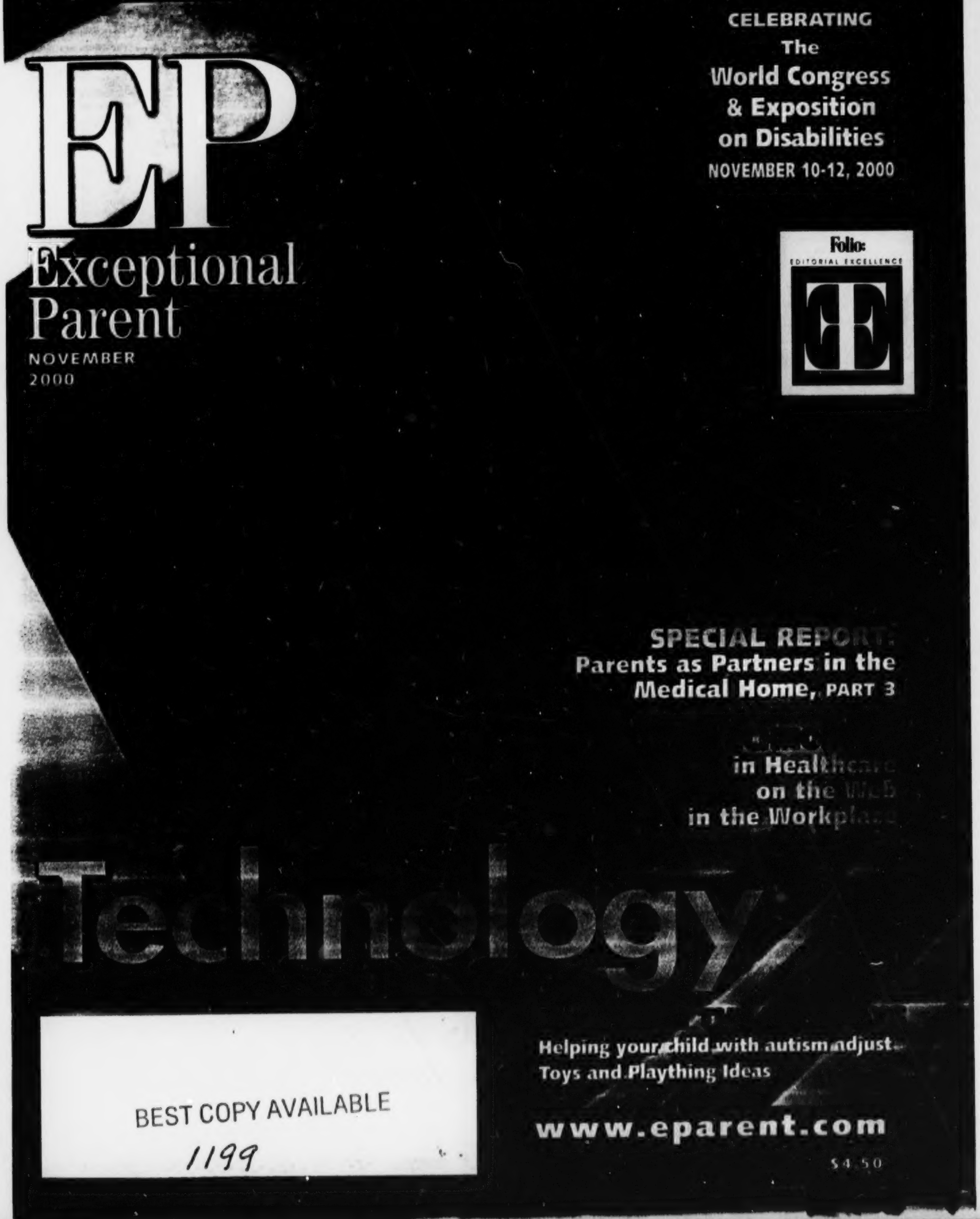

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Carnitine is a naturally occurring substance that's essential in the metabolic process. If the body is deficient in carnitine, the ability of the cells to produce energy and to remove toxic wastes is impaired. And while carnitine deficiency can be serious, its symptoms are hard to detect and are often overlooked.

Signs include muscle weakness, frequent infection, seizures, poor muscle tone, slow growth, speech difficulties, slow weight gain, lack of energy and developmental delay.

The only treatment for carnitine deficiency is Carnitor.®

Adverse events reported with Carnitor use include nausea, vomiting, body odor, gastritis and seizures. There are no reported contraindications or warnings. Refer to the prescribing information on the reverse page.

Poor muscle to
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Fortunately, most children will never develop carnitine deficiency. But any time you notice something that seems not quite right, talk with your child's doctor. After all, only you see the whole picture.

For more information, visit www.carnitor.com. Or call 1-800-447-0169.

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BRIEF SUMMARY
The following is a brief summary. Please see package insert for full prescribing information.

CLINICAL PHARMACOLOGY
CARNITOR® (levocarnitine) is a naturally occuring substance required in mammalian energy metabolism. It has been shown to facilitate long-chain fatty acid entry into cellular mitochondria, therefore delivering substrate for oxidation and subsequent energy production. Fatty acids are utilized as an energy substrate in all tissues except the brain. In skeletal and cardiac muscle they serve as major fuel. Primary systemic carnitine deficiency is characterized by low plasma, RBC, and/or tissue levels. It has not been possible to determine which symptoms are due to carnitine deficiency and which are due to the underlying organic acidemia, as symptoms of both abnormalities may be expected to improve with carnitine. The literature reports that carnitine can promote the excretion of excess organic or fatty acids in patients with defects in fatty acid metabolism and/or specific organic acidopathies that bioaccumulate acyl CoA esters.

Secondary levocarnitine deficiency can be a consequence of inborn errors of metabolism. CARNITOR® may alleviate the metabolic abnormalities of patients with inborn errors that result in accumulation of toxic organic acids. Conditions for which this effect was demonstrated are: glutaric aciduria II, methyl malonic aciduria, propionic acidemia, and medium chain fatty acyl CoA dehydrogenase deficiency. Autointoxication occurs in these patients due to the accumulations of acyl CoA compounds that disrupt intermediary metabolism. The subsequent hydrolysis of the acyl CoA compound to its free acid results in acidosis that can be life threatening. Levocarnitine clears the acyl CoA compound by formation of acyl carnitine which is quickly excreted.

Levocarnitine deficiency is defined biochemically as abnormally low plasma levels of free carnitine, (less than 20 µmol/L at one week post term) and may be associated with low tissue and/or urine levels. Further, this condition may be associated with a ratio of plasma ester/free levocarnitine levels greater than 0.4 or abnormally elevated levels of esterified levocarnitine in the urine. In premature infants and newborns, secondary deficiency is defined as plasma free levocarnitine levels below age related normal levels.

BIOAVAILABILITY/PHARMACOKINETICS
In a relative bioavailability study in 15 healthy adult male volunteers CARNITOR® Tablets were found to be bio-equivalent to CARNITOR® Oral Solution. Following the administration of 1980 mg b.i.d., the maximum plasma concentration level (C_{max}) was 80 nmol/mL and the time to maximum concentration (T_{max}) occurred at 3.3 hours. There were no significant differences for AUC and urinary excretion observed between these two formulations.

In the same bioavailability study of 15 healthy adult males, CARNITOR® (levocarnitine) Injection administered as a slow 3 minute bolus intravenous injection at a dose of 20 mg/kg showed that free levocarnitine plasma profiles are best fit by a two compartment model. Approximately 76% of free levocarnitine is eliminated in the urine. Using plasma levels uncorrected for endogenous levocarnitine, the mean distribution half life was 0.585 hours and the mean apparent terminal elimination half life was 17.4 hours following a single intravenous dose.

The absolute bioavailability of L-carnitine from CARNITOR® Tablets and Oral Solution was determined compared to the bioavailability of L-carnitine from CARNITOR® Injection intravenous in 15 healthy male volunteers. After correction for circulating endogenous levels of L-carnitine in the plasma, absolute bioavailability was 15.1% ± 5.3% for L-carnitine from CARNITOR® Tablets and 15.9% ± 4.9% from the Oral Solution.

Total body clearance of L-carnitine (Dose/AUC including endogenous baseline levels) was a mean of 4.00 L/hr. Endogenous baseline levels were not subtracted since total body clearance of L-carnitine does not distinguish between exogenous sources of L-carnitine and endogenously synthesized L-carnitine. Volume of distribution of the intravenously administered dose above baseline endogenous levels was calculated to be a mean of 29.0 L ± 7.1 L (approximately 0.39 L/kg) which is an underestimate of the true volume of distribution since plasma L-carnitine is known to equilibrate slowly with, for instance, muscle L-carnitine.

L-carnitine was not bound to plasma protein or albumin when tested at any concentration or with any species including the human.

INDICATIONS AND USAGE
CARNITOR® (levocarnitine) is indicated in the treatment of primary systemic carnitine deficiency. In the reported cases, the clinical presentation consisted of recurrent episodes of Reye-like encephalopathy, hypoketotic hypoglycemia, and/or cardiomyopathy. Associated symptoms included hypotonia, muscle weakness and failure to thrive. A diagnosis of primary carnitine deficiency requires that serum, red cell and/or tissue carnitine levels be low and that the patient does not have a primary defect in fatty acid or organic acid oxidation (see Clinical Pharmacology). In some patients, particularly those presenting with cardiomyopathy, carnitine supplementation rapidly alleviated signs and symptoms. Treatment should include, in addition to carnitine, supportive and other therapy as indicated by the condition of the patient.

CARNITOR® (levocarnitine) is also indicated for acute and chronic treatment of patients with an inborn error of metabolism that results in a secondary carnitine deficiency.

CONTRAINDICATIONS
None known.

WARNINGS
None.

PRECAUTIONS
General
CARNITOR® (levocarnitine) Oral Solution is for oral/internal use only.
Not for parenteral use.
Gastrointestinal reactions may result from too rapid consumption of carnitine. CARNITOR® (levocarnitine) Oral Solution may be consumed alone, or dissolved in drinks or other liquid foods to reduce taste fatigue. It should be consumed slowly and doses should be spaced evenly throughout the day to maximize tolerance.

Carcinogenesis, mutagenesis, impairment of fertility
Mutagenicity tests performed in *Salmonella typhimurium*, *Saccharomyces cerevisiae*, and *Schizosaccharomyces pombe* indicate that CARNITOR® (levocarnitine) is not mutagenic. Long-term animal studies have not been conducted to evaluate the carcinogenicity of the compound.

PREGNANCY
Pregnancy Category B.
Reproductive studies have been performed in rats and rabbits at doses up to 3.8 times the human dose on the basis of surface area and have revealed no evidence of impaired fertility or harm to the fetus due to CARNITOR®. There are, however, no adequate and well controlled studies in pregnant women. Because animal reproduction studies are not always predictive of human response, this drug should be used during pregnancy only if clearly needed.

NURSING MOTHERS
It is not known whether this drug is excreted in human milk. Because many drugs are excreted in human milk, a decision should be made whether to discontinue nursing or to discontinue the drug, taking into account the importance of the drug to the mother.

PEDIATRIC USE
See Dosage and Administration.

ADVERSE REACTIONS
Various mild gastrointestinal complaints have been reported during the long-term administration of oral L- or D,L-carnitine; these include transient nausea and vomiting, abdominal cramps, and diarrhea. Mild myasthenia has been described only in uremic patients receiving D,L-carnitine. Gastrointestinal adverse reactions with CARNITOR® (levocarnitine) Oral Solution dissolved in liquids might be avoided by a slow consumption of the solution or by a greater dilution. Decreasing the dosage often diminishes or eliminates drug-related patient body odor or gastrointestinal symptoms when present. Tolerance should be monitored very closely during the first week of administration, and after any dosage increases.

Seizures have been reported to occur in patients with or without pre-existing seizure activity receiving either oral or intravenous levocarnitine. In patients with pre-existing seizure activity, an increase in seizure frequency and/or severity has been reported.

OVERDOSAGE
There have been no reports of toxicity from carnitine overdosage. The oral LD_{50} of levocarnitine in mice is 19.2 g/kg. Carnitine may cause diarrhea. Overdosage should be treated with supportive care.

DOSAGE AND ADMINISTRATION
CARNITOR® (levocarnitine) Tablets.

Adults: The recommended oral dosage for adults is 990 mg two or three times a day using the 330 mg tablets, depending on clinical response.

Infants and children: The recommended oral dosage for infants and children is between 50 and 100 mg/kg/day in divided doses, with a maximum of 3 g/day. Dosage should begin at 50 mg/kg/day. The exact dosage will depend on clinical response.

Monitoring should include periodic blood chemistries, vital signs, plasma carnitine concentrations and overall clinical condition.

CARNITOR® (levocarnitine) Oral Solution.
For oral use only. **Not for parenteral use.**

Adults: The recommended dosage of levocarnitine is 1 to 3 g/day for a 50 kg subject, which is equivalent to 10 to 30 mL/day of CARNITOR® (levocarnitine) Oral Solution. Higher doses should be administered only with caution and only where clinical and biochemical considerations make it seem likely that higher doses will be of benefit. Dosage should start at 1 g/day, (10 mL/day), and be increased slowly while assessing tolerance and therapeutic response. Monitoring should include periodic blood chemistries, vital signs, plasma carnitine concentrations, and overall clinical condition.

Infants and children: The recommended dosage of levocarnitine is 50 to 100 mg/kg/day which is equivalent to 0.5 mL/kg/day CARNITOR® (levocarnitine) Oral Solution. Higher doses should be administered only with caution and only where clinical and biochemical considerations make it seem likely that higher doses will be of benefit. Dosage should start at 50 mg/kg/day, and be increased slowly to a maximum of 3 g/day (30 mL/day) while assessing tolerance and therapeutic response. Monitoring should include periodic blood chemistries, vital signs, plasma carnitine concentrations, and overall clinical condition.

CARNITOR® (levocarnitine) Oral Solution may be consumed alone or dissolved in drink or other liquid food. Doses should be spaced evenly throughout the day (every three or four hours) preferably during or following meals and should be consumed slowly in order to maximize tolerance.

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EP

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EDITORIAL MISSION

- TO REACH OUT TO MOTHERS AND FATHERS OF CHILDREN AND YOUNG ADULTS WHO HAVE DISABILITIES AND SPECIAL HEALTHCARE NEEDS.
- TO EMPOWER PARENTS AND PROFESSIONALS BY PROVIDING PRACTICAL INFORMATION AND EMOTIONAL SUPPORT.
- TO APPRECIATE THAT PARENTS ARE THE MOST IMPORTANT EXPERTS IN THE LIVES OF THEIR CHILDREN.
- TO ENERGIZE PARENTS AND PROFESSIONALS.
- TO SHARE IDEAS AND EXPERIENCES SO PARENTS, PROFESSIONALS, PEOPLE WHO HAVE DISABILITIES, AND OTHER ADVOCATES CAN LEARN FROM ONE ANOTHER AND BETTER COLLABORATE TO SERVE ALL CHILDREN AND FAMILIES.

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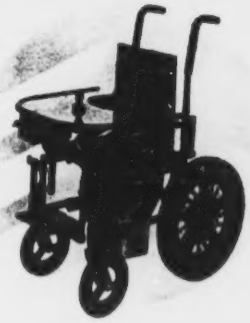

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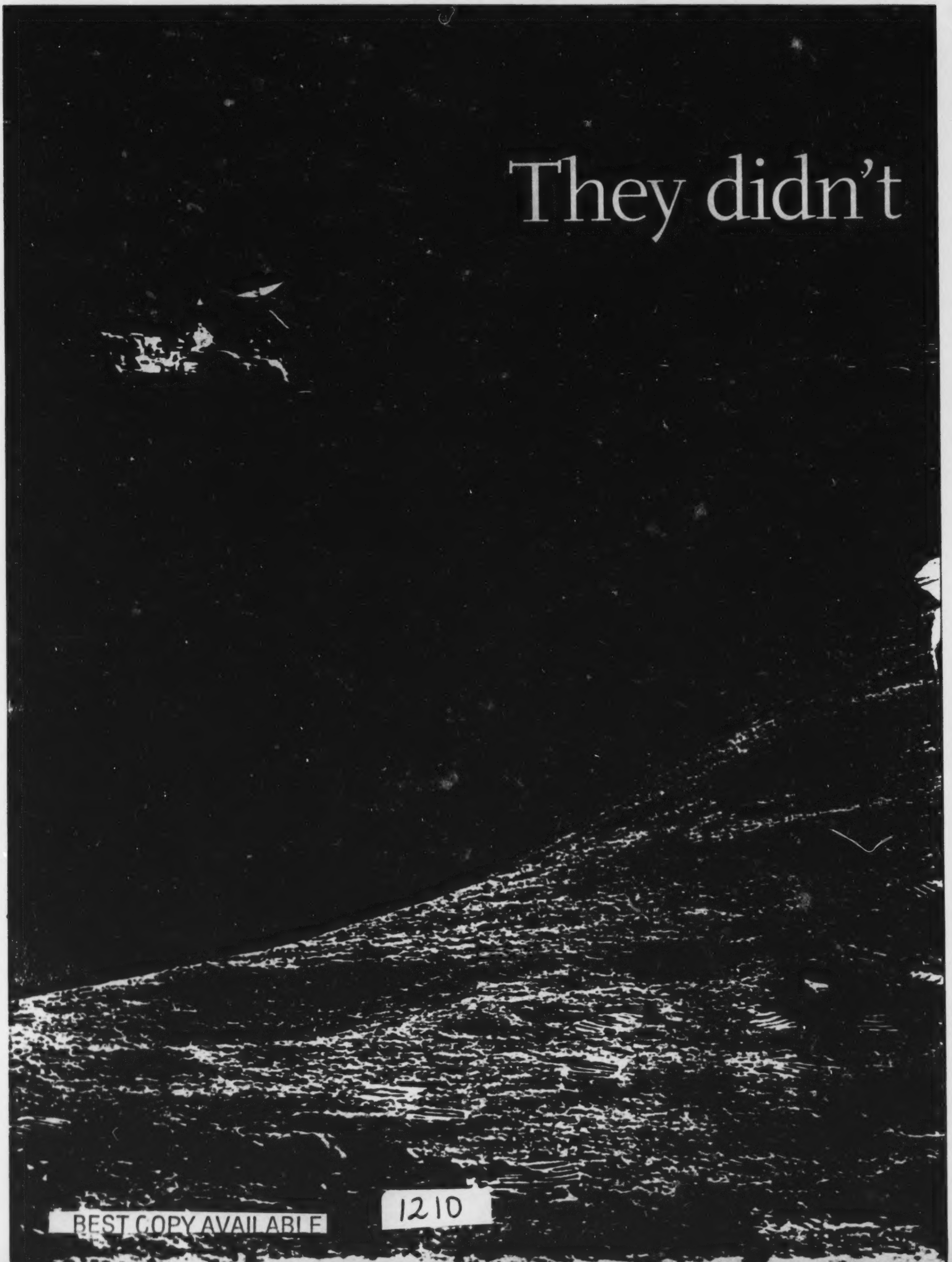

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editor's desk

THE MISSION CONTINUES

RICK RADER, MD

Several years ago I was attracted to, and eventually seduced by, an intriguing ad in a prestigious medical journal. It read, "Aggressive, creative physician wanted to help create the next generation of habilitative services to a medically fragile population." Weeks later, I flew down to Chattanooga, Tennessee, at the invitation of the Board of the Orange Grove Center for an initial "look-see."

Orange Grove Center was started in 1953 by concerned parents of "crippled and retarded children." People-first language was not high on their agenda; creating services for their forgotten and invisible children was. At that time, it was illegal to send "crippled and retarded" children to public schools. So, with a donated, abandoned school building, parents and their children came together, rolled up their sleeves, and created a school.

Exceptional parents? No, just parents doing what needed to be done. If it weren't for the coining of the term "exceptional" in the late 60s, you might be holding a copy of the November 2000 issue of "*DP*"—"Desperate Parents." These pioneering parents, now octogenarians, are quick to point out that much of their work was done by the seat of their pants. They were tired of waiting—not unlike the current generation of exceptional parents who are creating their own programs and solutions in the many areas still not being adequately addressed.

Orange Grove never stopped growing. In addition to the school, they created a comprehensive healthcare center, dental clinic, full therapy services, including vocational, residential, behavioral, music, art, recreational, and counseling services. Programs in staff and professional development, assistive technology, community inclusion, physical and nutritional management, ICF/MR, social work, assisted living, transition planning, and parent support were also developed. The Orange Grove students were not only living longer, they were thriving. These "kids" were maturing, and Orange Grove had to go back to the drawing board to meet emerging demands.

They needed a dedicated department to help identify evolving biopsychosocial dynamics, address changing community and societal expectations, and integrate emerging technologies. They realized the need to expand caregiver and parent training, to harness medical informatics (the integration of databases in medical decision-making), decipher evidence-based practices, and come to grips with outcomes. And so they placed that ad.

Flash forward. It's been seven years since I became the first director of Orange Grove's Morton J. Kent Habilitation Center. The word "habilitation" is from the Latin "habilis," meaning to make suitable or to make fit. It aptly describes what we do: create programs and strategies that address the needs of individuals with disabilities in becoming part of the community, as well as the needs of the community in embracing them.

My cross training in both anthropology and medicine allows me to see the disabilities arena in the context of it being a unique and distinct culture. It's a culture with its own set of values, tools, art, language, stratification, priorities, and history. It has provided the framework for an appreciation of the cultural determinants of human exceptionality, performance, and attainment.

In becoming conversant in developmental disabilities (no thanks to the 30-minute slide show most medical students receive), I happened onto Exceptional Parent magazine. I initially looked at it as a place to learn the latest politically correct jargon, the buzzwords, hot issues, and the key players. While I did learn those things, I learned something else as well: how parents had "led the way"; that parent persistence, advocacy, and perseverance have had as dramatic an impact on health as handwashing; that parent-generated programs have been the impetus to a cultural revolution that rivaled the invention of moveable type.

I began to cross-pollinate ideas from EP with those from Orange Grove and vice versa. I made room amid my shelves of *JAMA* and *The New England Journal of Medicine* for growing piles of EP. I wrote articles, made suggestions, served on committees, and eventually accepted an invitation to join the EP Editorial Advisory Board. With the unexpected and tragic loss of EP founder Dr. Max Schleifer, I have been asked to assume the position as the new editor-in-chief of EP.

While it has become customary for incoming "heads" to promise to make a "seamless transition" in their new position, I need to disclaim that idea. I think leadership (and history) needs "seams." It is one way of honoring and demarcating previous successes. There will be seams, but hopefully seams that will make the fabric of EP's future even stronger.

Despite the full-time demands of the role of the editor-in-chief, I am still committed to the ongoing work at Orange Grove. Having an editor-in-chief grounded in the day-to-day workings of one of the country's most dynamic and innovative community agencies in the field of developmental disabilities can help keep EP buzzing with excitement and validity.

My coming to this position would not be possible, however, without the support of the Board of Directors at Orange Grove who not only permitted me to assume this position, but encouraged me. In particular, I want to single out the board of the M.J. Kent Habilitation Center: Mort Kent, Tom Caldwell, and John Germ. To these "mavericks in suits," visionaries and agents of change, thanks for building a place I wanted so much to find.

Thanks also to Mike Cook and Hal Baker, executive and deputy directors respectively; and to Dianne Aytes, our deputy director and chief financial officer. And to Susan Jenkins, my executive assistant. She keeps me focused, grounded, and organized (not to mention sharing her chocolate with me).

In keeping with the practice of physicians offering "disclosures" to help audiences appreciate possible conflicts or bias, I want to acknowledge that I am not a parent of a child with special healthcare needs. In fact, I'm not a parent. Thus I do not say, "I understand," or " I know how you feel." I don't. Everything that I "know and understand" about parenting I acquired directly from parents: working with them, crying with them, teaching them, learning from them—and, yes, being humbled by them.

I have seen many parallels between the work of Orange Grove and that of EP. I think that the mission statement at Orange Grove is one example that sums it up. It superbly captures the universe of parents, professionals, and EP staffers who have dedicated their lives and careers to caring for children and adults with special healthcare needs: "To recognize, support, and celebrate the qualities of the individual." I always keep it handy and will continue to be guided by it.

Finally, I want to dedicate my editorial efforts at EP to Ernie and Sylvia, my own exceptional parents, with the hope that they know how deeply they are both missed.

Rick Rader, MD

Rick Rader, MD
Editor-in-Chief

EDITOR'S NOTE: Rick is a member of the Medical Division of the American Association on Mental Retardation, a Fellow Member of the American Academy of Cerebral Palsy and Developmental Medicine, a Fellow of the American Institute of Stress, the Society of Teachers of Family Medicine, and The New York Academy of Sciences. He is a consultant to the Vice President's Expert Panel on Family Centered Care, a participant in the public policy forum of the National Institutes of Health and on the Steering Committee of the National Alliance for Direct Support Professionals.

It is our honor to welcome Rick into his new role as editor-in-chief. We are grateful that he has taken on this new responsibility. Rick's abiding personal commitment, as well as his outstanding professional credentials, will ensure that EP continues to serve its readers in caring for the special children in their lives.—The EP STAFF

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Dianna Fitzgerald
& Her Son Nicholas

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Dianna Fitzgerald

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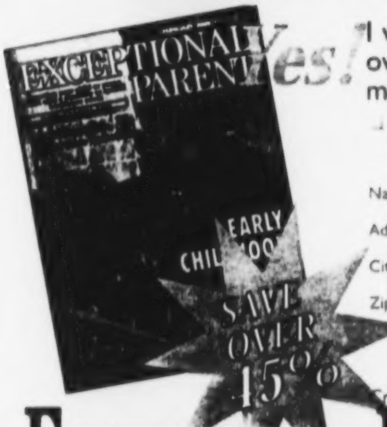

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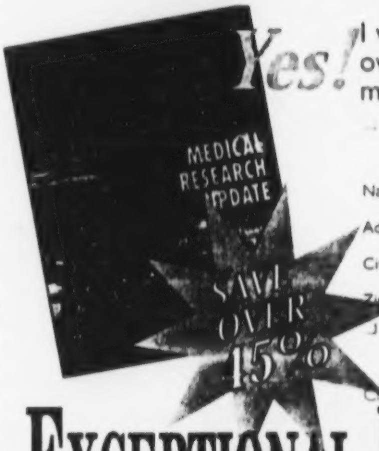

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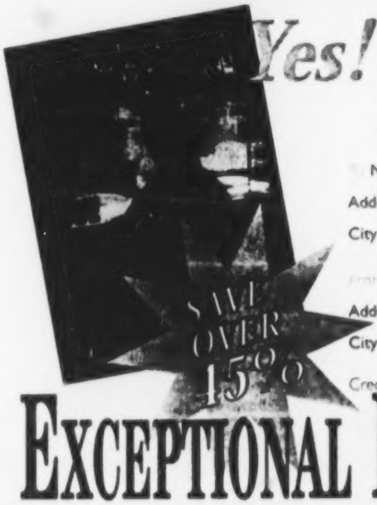

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Exceptional Parent

is the magazine for parents and professionals involved in the care and development of children and young adults with special needs, including Physical Disabilities, Developmental Disabilities, Mental Retardation, Autism, Epilepsy, Learning Disabilities, Perceptual Disabilities, Hearing Impairments, Vision Impairments, Emotional Problems, Chronic Illness.

Exceptional Parent's MISSION IS TO:

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INFORM
parents and professionals about current and changing rights, laws and programs for children and young adults with disabilities, and their families;

SERVE
as a network, a forum for the exchange of ideas, experience and advice between parents, professionals and educators;

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Search & Respond

About Search & Respond

Search and Respond is an opportunity for our readers to exchange information about their practical experiences in meeting the everyday challenges of life with a child or adolescent who has a disability. In this column, "S" represents Search letters and "R" represents Respond letters received to a previously printed Search. "Instant S&R" is a new feature which represents e-correspondence we have downloaded from our Web site. All Responds are forwarded to the writers of the original Searches; some are published. Published letters may be edited for purposes of space and clarity. We also expect parents to consult appropriate professionals.

When sending correspondence, please indicate whether it is a Search or a Respond. For Responds, be sure to note in which issue the original Search letter appeared. Please remember to include a phone number on all correspondence, in the event that more information is required. Write to: Exceptional Parent, Attn: Search/Respond, 555 Kinderkamack Rd., Oradell, NJ 07649-1517; Fax to: (201) 634-6570; E-mail to epedit@aol.com; or visit Search and Respond on our Web Site: http://www.eparent.com.

For information about specific disabilities, contact: the National Organization for Rare Disorders (NORD), 100 Rt. 37, PO Box 8923, New Fairfield, CT 06812; (800) 999-6673; (203) 746-6518; Web site: http://www.rarediseases.org. Also, see the "National Resources for Specific Disabilities" directory in Exceptional Parent's 2000 Resource Guide (January 2000, starting on page 30).

Each month, Chris Feudtner, MD, PhD, reviews Search & Respond for accuracy and completeness. Dr. Feudtner is a pediatrician at the Pediatric Care Center of the University of Washington in Seattle, and is currently a Robert Wood Johnson Clinical Scholar. Look for Dr. Feudtner's comments on certain Search & Respond letters.

S

Limb lengthening vs. amputation

My 4-year-old son has one femur that is dramatically shorter than the other. His hip did not form properly, and he has a severe contraction of the hip and an unstable knee joint. We have sought several options about limb lengthening and have basically been given two choices. The first is that we could go ahead with the limb lengthening, which is a painful procedure and would have to be done at least two or three times to be helpful. If his contraction cannot be eliminated by surgery, it would make the surgery worthless. The other choice is to amputate his foot (his foot has no problems), fuse his knee, turn his ankle into a knee joint, and have a prosthetic device for his tibia and foot. I am terrified of making the wrong choice for my son, and I want to do what is best for him.

BB, via the EP Web site

S

Where to go for vacation

My daughter is 8 years old, has cerebral palsy, and has mental retardation. She is nonverbal and totally dependent on me for all her needs. My husband and I are trying to plan a vacation for next year. We thought of Disney World, but she is highly sensitive to noise, so we do not think it is an appropriate place to go. Does anyone know of any places where we can go?

Eileen, via the EP Web site

S

Daughter needs stability while walking

I have a 3-year-old daughter. Although she had a difficult birth (with a prolapsed umbilical cord), EEG, EKG, CT, and MRI results were all normal. Her fine motor skills have been affected, however. Until now, therapists and neurologists have all called it "hypotonia," but she has leg muscles that are developing well. She is above average cognitively but very unstable physically. Weakness kept her from even rolling over until she was 18 months old. She began crawling around 2, and shortly thereafter started walking, but was very wobbly. She has been walking for over a year, but she is easily tipped, and walks with a "drunken" gait. The latest term her therapists have come up with is "ataxia" (the inability to perform coordinated muscle movements). Is this a common outcome of a difficult birth? How is her ataxia related to this? What can I do to help her gain stability?

PM, via the EP Web site

Respond

R

Car seat

Lisa (July 2000) has a 2-year-old son with spinal muscular atrophy and severe hypotonia. She was looking for a forward-facing car seat that would provide adequate head and neck support.

I have a 3-year-old son with spinal muscular atrophy. I suggest the Columbia 2000 with base. It supports 20-100 lbs, has cloth seat covers, and is light weight. The base is good because it maneuvers very well, and is also light weight, but sturdy. The seat cost me about $1600, but I got a local organization to help me with the cost.

Jennifer, via the EP Web site

R

Our son is 4 years old and has low muscle tone. We found that the Snug Seat® 1000 car seat works well, because it can be reclined a bit while facing forward.

Kathy, via the EP Web site

R

You might also look into the E-Z On™ Vest, which can be attached to your seat belts in a way to allow your child to lie down in the back seat.

KB, via the EP Web site

EDITOR'S NOTE:
Here is the contact information for the companies mentioned above:

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Web site: http://www.columbiamedical.com

Snug Seat, Inc.
(800) 336-7684
Web site: http://www.snugseat.com

E-Z-On Products, Inc., of Florida
(800) 323-6598
Web site: http://www.ezonpro.com

continued on page 20

Search & Respond

continued from page 19

R

Potty training

KS (July 2000) has a 5-year-old son with autism and wanted to know how to get him to understand that it is okay to use the toilet.

I am the parent of a 6-year-old boy with autism who has had success in potty training. My first piece of advice is to purchase or rent the videotape "It's Potty Time" and have your son watch it on a repeated basis.

My son's teacher suggested we simply keep him in the bathroom until we achieve success. So, on a Saturday morning, I brought him into the bathroom, looked him in the eyes, and told him that he was getting too big to wear diapers, that I loved him, and that today was the day he was going to learn to go to the bathroom in the toilet. I was very firm in my approach. I did not make him sit on the toilet the entire time; he could get up and move around in the bathroom, but could not leave until he used the toilet successfully. I took a small chair into the bathroom and read my mail, wrote some letters, and continued to tell him verbally what was expected. After 4 hours in the bathroom and two accidents on the floor, my son finally used the toilet!

After each accident, I repeated that urine goes in the toilet, and that when he urinated in the toilet he could go outside and play with his sister.

After the first success, I gave him a huge amount of praise, which he loved. I then allowed him to go out and play for one hour. After the hour was up, he went back into the bathroom. Again, I told him that he was not going to leave until he had success. This time it only took about 10 minutes. From that point on, it became much easier for him, and now I simply schedule his toileting times. He is now dry 100 percent of the time, unless I forget to keep him on schedule. We are still not 100 percent with bowel movements yet, but I am confident that someday we will be.

Karen, via the EP Web site

> *DR FEUDTNER:*
> *Although this method was a success for this particular family, it is important to remember that each child is different, and in general, parents should try to avoid any scenario that could involve stress. Using behavior modification with positive rewards to help a child learn a new, complicated behavior like urinating in a toilet, requires us to 1) break that behavior down into little steps; 2) provide opportunities for the child to "accidentally" perform the next step; 3) reward the child incrementally for accomplishing each step; and 4) gradually move along until the final behavior is completed. In this instance, staying in the bathroom gave the child plenty of opportunity while the praise was a powerful reward, and the gamble of saying "we are staying in here until you urinate in the toilet" paid off. An alternative would be, as a first step, to reward with praise any urination that took place in the bathroom, and then start to work toward urinating in the toilet. This process will differ for every family and will always require tremendous creativity, patience, and love.*

Instant S&R

S

Athletic programs for son with cerebral palsy

I am the mother of a 5-year-old boy who has cerebral palsy. I am having a very hard time trying to find some kind of sports program for him to join in Brooklyn, NY. So far, no one that I have asked, even in his school, knows of anything around here. Last year, I had to take him to NJ to be on a basketball team. If anyone has any information on any kinds of programs please let me know.

Denise, via the EP Web site

R

Check out the Boys and Girls Clubs in your area. Ours (in Michigan) offers a league called Youth Abilities League. It is very well run. The volunteers do all the work and the parents get a chance to talk with each other and cheer their kids on without actually having to help out.

BY, via the EP Web site

> *EDITOR'S NOTE:*
> *There are several organizations that may be able to help.*
>
> *United States Cerebral Palsy Athletic Association*
> *http://www.uscpaa.org*
>
> *National Wheelchair Basketball Association*
> *http://www.nwba.org*
>
> *Wheelchair Sports USA*
> *http://www.wsusa.org*
>
> *World T.E.A.M.*
> *http://www.worldteamsports.org*

S

Excessive mouthing

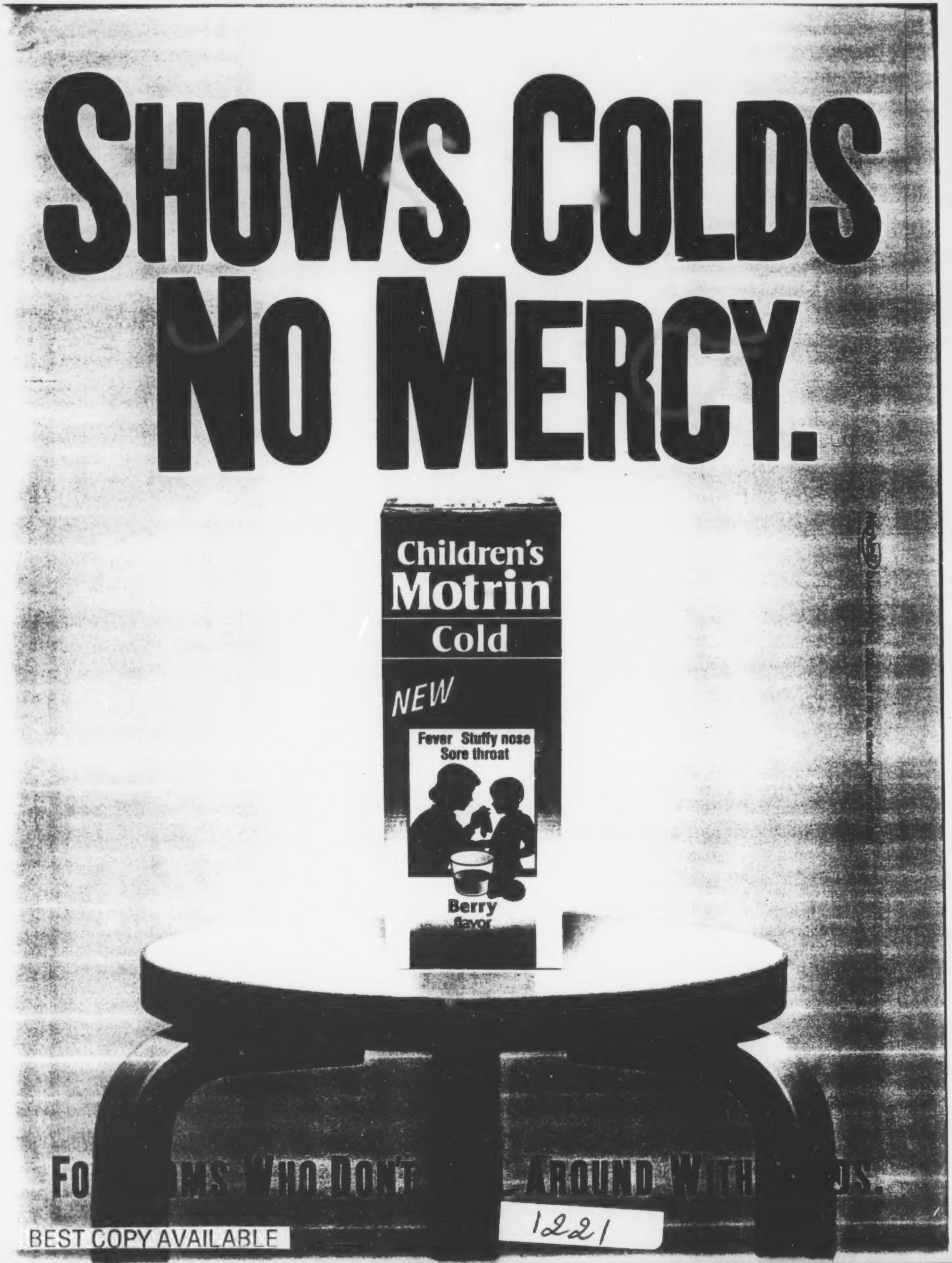
My daughter is 3 years old and has periventricular leukomalacia (also called PVL—the softening of brain tissue near the ventricles that occurs because brain tissue in this area has died. PVL can result in physical and developmental delays, and impaired vision or hearing), cerebral palsy, and cortical visual impairment, among other things. She is very oral—she constantly tries to put everything into her mouth and chew. We initially attributed that to her lack of vision, but her vision is improving while her tendency to mouth everything is not. I would like to know what tactics other parents use to reduce excessive mouthing, and what leads a child to engage in that behavior.

Anonymous, via the EP Web site

R

My 10-year-old son has multiple disabilities and mouths everything, too. An infant's first method of exploration is his or her mouth. While our kids are not infants, they need to use every method to explore their world. I would suggest letting your child hold large objects that provide lots of tactile stimulation. It helped our son. Also, remember that some children are still cutting teeth. All that chewing helps to ease the gum discomfort they cannot tell us about. Have you tried toddler biter biscuits? At least they are digestible.

Barb, via the EP Web site



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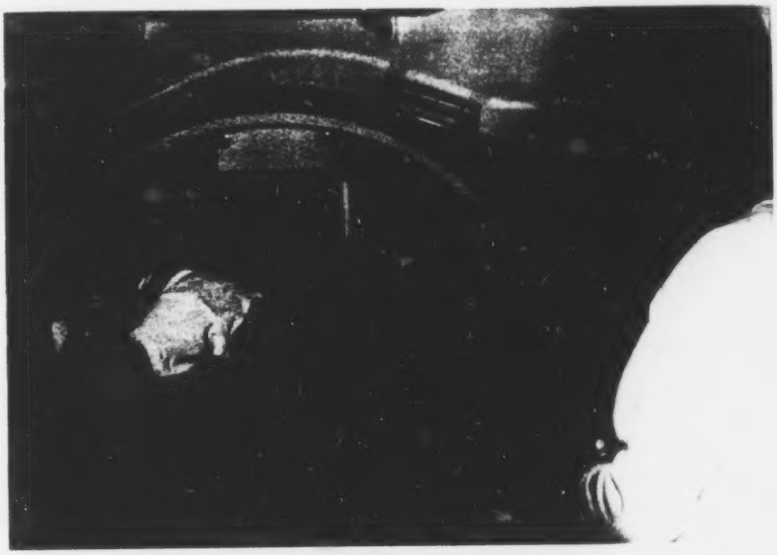

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- Brady Institute at Jamaica Hospital
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2001 technology

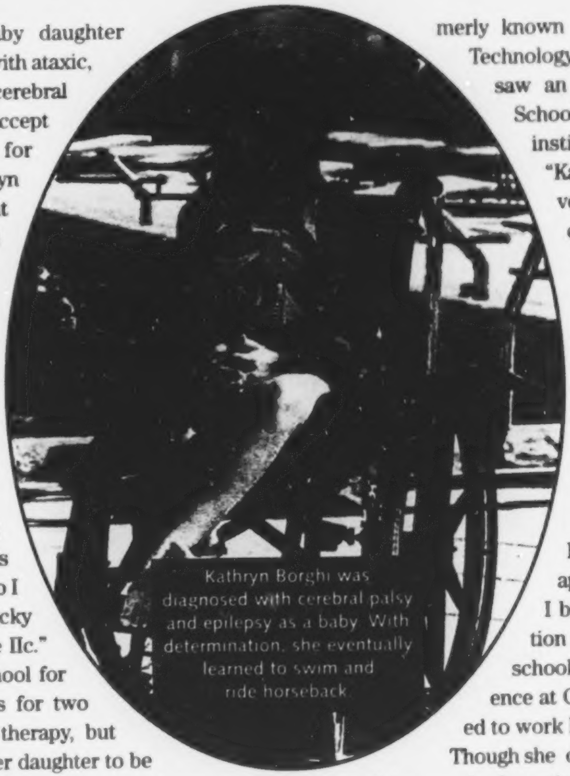
SEEING PAST A CHILD'S DISABILITY

When Hope Borghi's baby daughter Kathryn was diagnosed with ataxic, hypotonic, hemiplegic cerebral palsy, and epilepsy, she refused to accept the doctor's bleak predictions for Kathryn's future. From the day Kathryn was born, Hope filled her environment with love, music, excitement, and visual, and motor stimulation. "Without intending to do so," she says, "I had already begun to provide the stimulation that enabled Kathryn to reroute her mental energy to different areas of her brain." This way of responding, Hope believes, proved crucial to her daughter's later development.

"In the early '80s, I discovered that the computer was the only answer as an alternative means of expression, so I had Kathryn in a high chair using 'Sticky Bear Numbers' at age 3 on an Apple IIc." Kathryn attended an elementary school for children with orthopedic challenges for two years, receiving intensive physical therapy, but Hope was adamant about wanting her daughter to be educated in a general education classroom. She pushed successfully to get Kathryn enrolled in public school in the Borghis' hometown of Upper Arlington, Ohio—unheard of at the time for a child with moderate cerebral palsy. Eventually, Hope's belief in the power of the computer to help her daughter led her to CAST, formerly known as the Center for Applied Special Technology, in Peabody, Massachusetts. Hope saw an ad for a CAST/Harvard Graduate School of Education "New Tools" summer institute and registered immediately. "Kathryn's epilepsy in those days was very debilitating. My husband, Peter, committed time off so I could attend." That same summer, the Borghis enrolled Kathryn and her younger sister, Sarah, in CAST's annual one-week computer camp for children with disabilities and their siblings.

Hope says the family's experience at CAST that summer "strengthened my resolve and gave me the additional skills I needed to better educate and advocate for Kathryn. One of the occupational therapists at CAST did an evaluation, which I brought back to Ohio for implementation in Kathryn's classroom in the 1990-91 school year. From Kathryn's positive experience at CAST's summer course, I was motivated to work harder to get her teachers involved."

Though she did not realize it, Hope had begun practicing—and advocating for—Universal Design for Learning (UDL), a promising new approach to education that has gained momentum since the 1997 IDEA (Individuals with Disabilities Education Act) Amendments mandating access to the general curriculum for students with disabilities. The UDL approach uses the



Kathryn Borghi was diagnosed with cerebral palsy and epilepsy as a baby. With determination, she eventually learned to swim and ride horseback.

One Parent's View of Universal Design for Learning

by Lucinda M. O'Neill

1226

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flexibility of computers and the Internet to fashion software tools, educational content, and instructional approaches that support individualized learning. These tools and approaches provide alternatives for students with wide disparities in their abilities, backgrounds, and learning styles. For example, textbooks that are provided in electronic format can be used with text-to-speech software programs and screen readers, making the curriculum accessible to students with learning differences such as physical challenges, low vision or blindness, learning disabilities, and limited proficiency in English.

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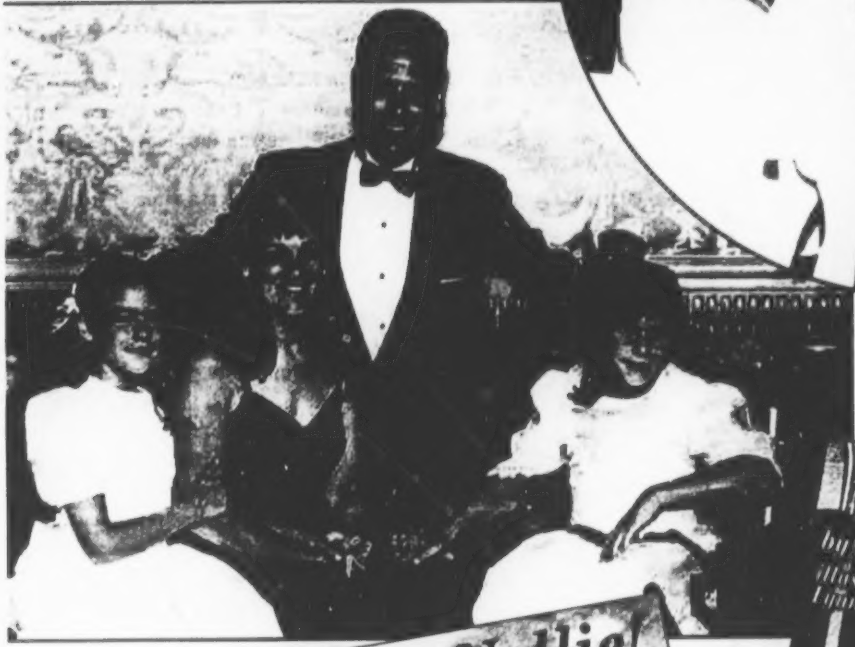
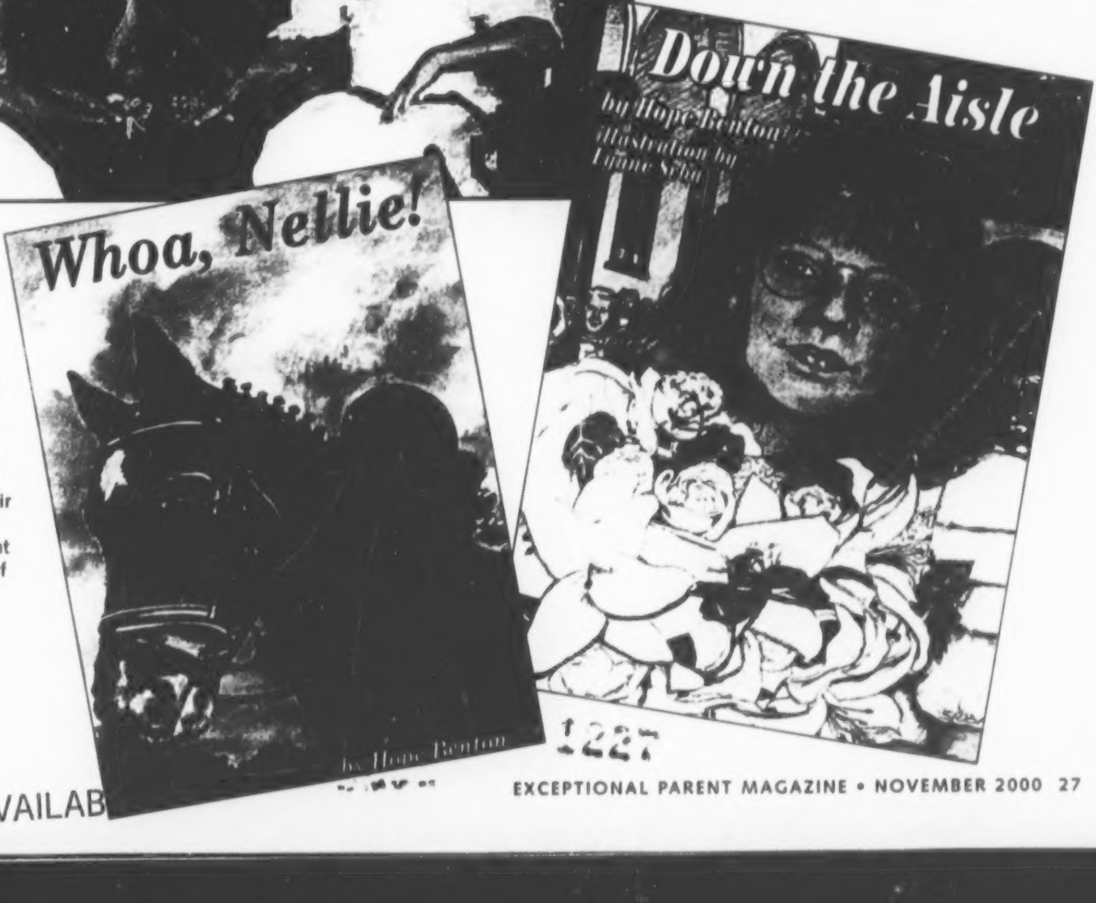
Above: Kathryn dances in her wheelchair at a family wedding.



Left: The Borghi family in 1995. (l to r) Sarah, Hope, Peter, and Kathryn.

Hope Borghi's fictional stories based on Kathryn's experiences serve as models for "inclusion of all children regardless of their particular challenges in life." Shown at right are covers from two of her books.



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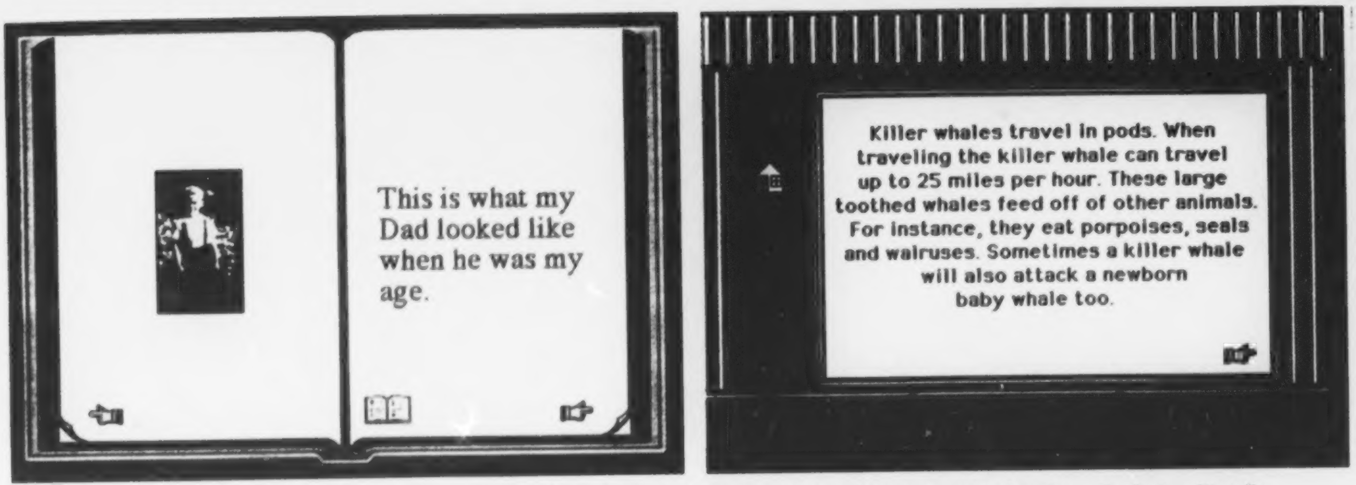

This is what my Dad looked like when he was my age.

Killer whales travel in pods. When traveling the killer whale can travel up to 25 miles per hour. These large toothed whales feed off of other animals. For instance, they eat porpoises, seals and walruses. Sometimes a killer whale will also attack a newborn baby whale too.

Above are screen shots from the software program HyperStudio™, which Kathryn used to deliver a report to her class—the first multimedia presentation in her school.

Thanks to Hope's advocacy, the four special needs tutors in Kathryn's elementary school were given computers and software along with training in how to use them. "Eventually, Kathryn's inclusion in a mainstream classroom had a substantial impact," recalls Hope. "At each new level, obstacles to learning occurred. Kathryn and I met them head on, and helped the staff and administration to hear what we were saying, and what CAST helped us to learn. Luckily, with vigilance and persistence, Kathryn succeeded." In 1995, unable to deliver a speech as her classmates did, Kathryn gave the first multimedia presentation in her school, using HyperStudio®, a computer software program. Though she was unable to take notes in class, Kathryn earned A's in seventh grade biology and made the honor roll all through middle school. In art class, her teacher set her up at a light table to trace pictures while the other students in the class drew free hand. Hope's drawing required endless repositioning of her pencil because of the involuntary movements caused by her cerebral palsy, but she persevered. The artwork she produced in the class went on to win prizes in national and international competitions sponsored by Very Special Arts (VSA Arts).

During those years, Hope published three books about Kathryn and another book about a brother who is hearing impaired. "While raising Kathryn, I hoped that I could change attitudes through literature. I wanted to [write] real-life inclusion stories where the emphasis is on the child, not on the disability." Hope's story, *Down the Aisle*, for example, focuses on Kathryn's unique experiences as a junior bridesmaid in a wedding. Kathryn read all of her mother's books before publication, giving her reactions and advice .

In December 1996, Kathryn died unexpectedly at the age of 15 from a viral illness that was complicated by her physical disabilities. "I miss her more than anything in life," Hope says today. "I learned more

continued on page 30

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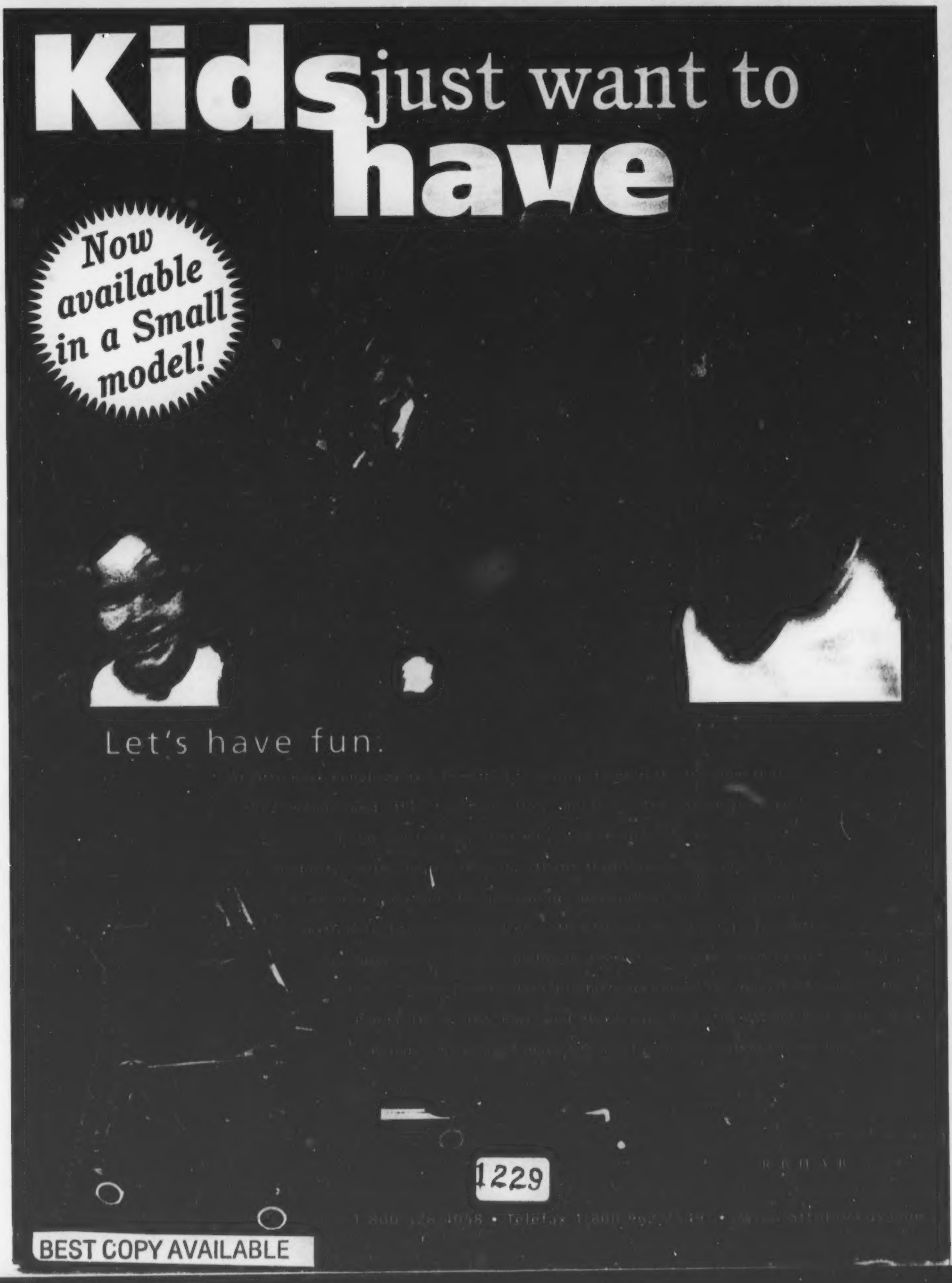

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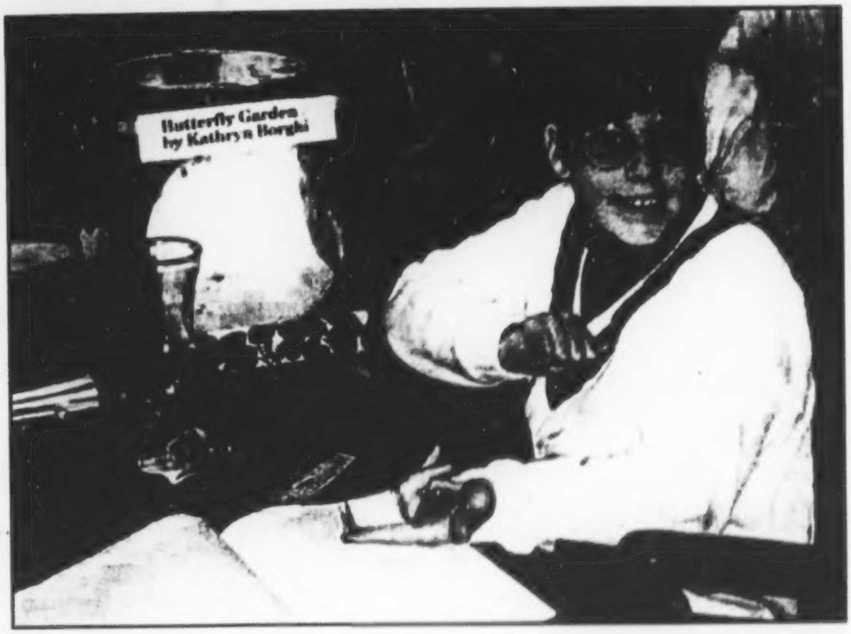

Kathryn displays her six grade science project on butterflies. She was a steady honor student during her three years at Jones Middle School.

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about life, love, happiness, true joy while sharing her life and raising her. She never gave up. Her innate humor and ability to share her joy and happiness taught me how to teach."

Today, Hope continues on the path she chose to follow while Kathryn was alive, advocating passionately for the inclusion of students with disabilities in general education classrooms. The Borghis have started an endowment fund in Kathryn's memory to benefit children with disabilities, and Hope has established OpenMinds™ Inc., a company that publishes fiction based on true stories of inclusion.

Kathryn Borghi with her classmates at her June 1994 graduation from elementary school. Hope Borghi worked hard to show school administrators that, with an aide, her daughter could do the work other children did in regular classrooms.

Faced with the barriers inherent in the traditional print-based general education curriculum most parents of children with disabilities want to know how they can better advocate for their kids in inclusive classroom settings. Universal Design for Learning offers a promising place to start.

First, if a school curriculum that is inclusive, flexible, and accessible, is better able to meet the child's educational needs even though he or she may be learning differently from their peers. Second, if the curriculum provides alternatives, it will be easier for parents to advocate for the use of these alternatives with their own children. In fact, a curriculum that incorporates UDL features can serve as a framework for parents' discussions with teachers, guidance counselors and academic department heads about how the child's learning needs are or are not being met. Third, UDL offers the possibility that assessments will be more flexible and that grading will not be based solely on test and quiz scores. Finally, by facilitating communication between school and home, the UDL model actively encourages parent participation in their children's academic development.

In Concord, New Hampshire, a district-wide project that converts curriculum to digital format relies heavily on parent volunteers to do the text and image scanning necessary to prepare UDL materials for students with disabilities in the schools. The project has been a key vehicle for getting parents excited about the UDL approach, even those students without special needs. "Parents of students with disabilities have gotten involved [through the project] or have been catalysts for getting their friends or other parents from the school involved in these efforts," observes Donna Palley, the special education coordinator who heads the project.

While Concord is successfully implementing the UDL system-wide, many school districts have yet to hear about Universal Design for Learning or have mistaken notions about what it is. Again, parents can be the driving force to get the message across. "Don't underestimate the power of knowledgeable parents to put tension on the system," says Palley. As her 15 years in the Concord Schools have shown her, and Hope Borghi's story so eloquently illustrates, big changes often start with individual students and their parents. "Every special education coordinator in the universe knows parents who have pushed their school district to improve or to change or to have something happen," says Palley, citing one parent of a student with a disability who is not only disabled herself but is also a disabilities rights attorney. "You can imagine that that parent is

continued on page 32

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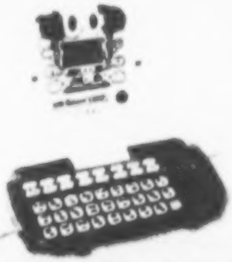

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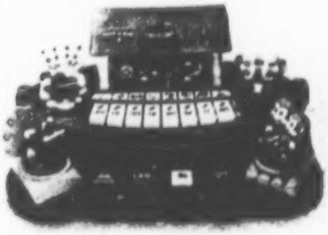

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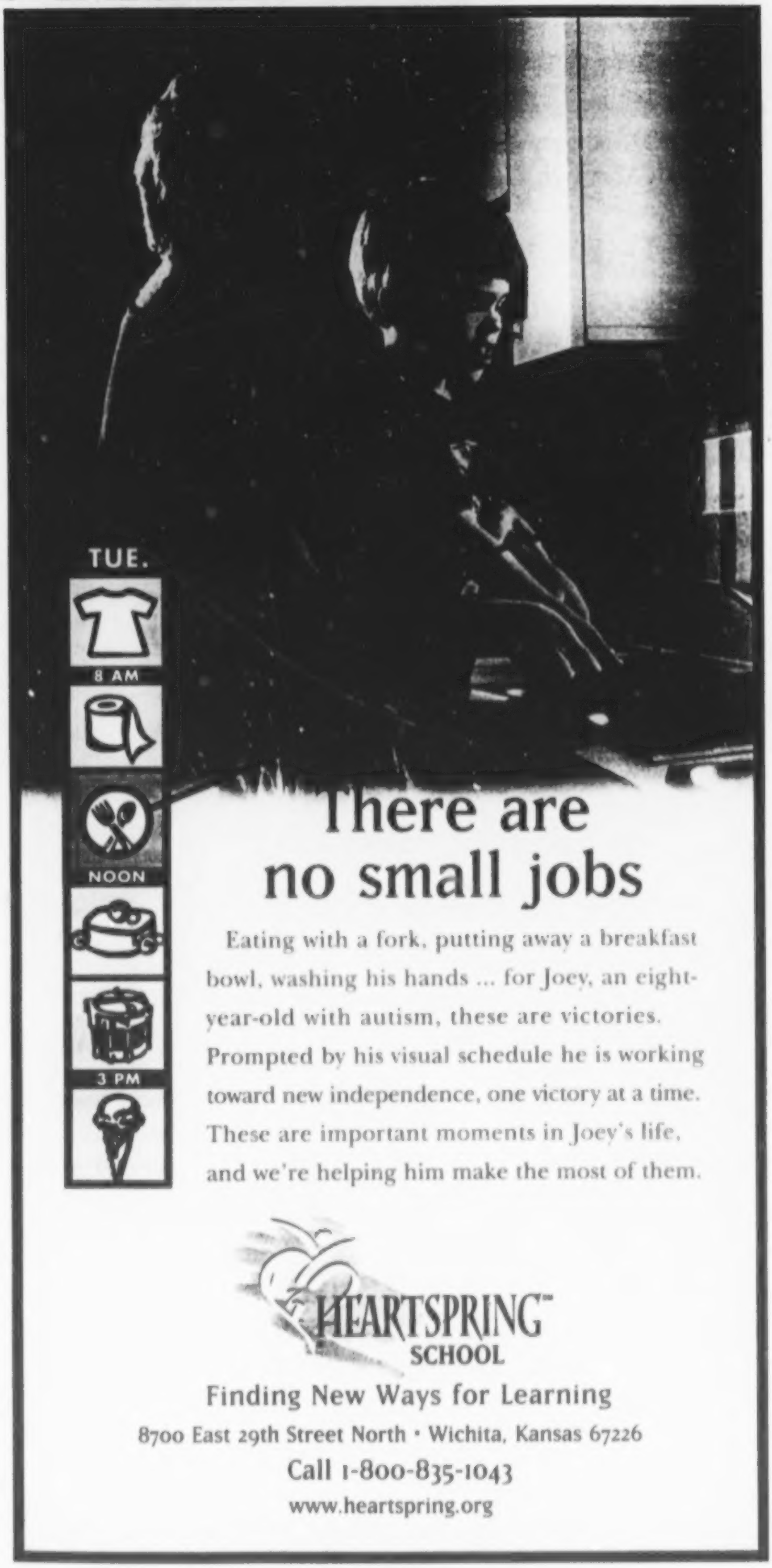

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someone who keeps me on my toes."

Hope Borghi speaks from her own experience in dealing with schools, counseling parents to "try to help them see the benefits of UDL, not just make demands."

Why should parents push for UDL in schools? Borghi believes that Universal Design for Learning is vital not only to the academic progress of students with disabilities but to their social development as well. "If Kathryn had tried to represent what she knew without a computer or Universal Design for Learning, she would have appeared to be much less than the person she was. Universal Design for Learning allowed her to put her best foot forward rather than her worst and helped her teachers and the other kids to see past her disability to who she really was." ■

Lucinda M. O'Neill is a staff writer at CAST.

Resources

For information about **CAST's** summer computer camp for children aged 11-18, contact Ann Brennan by phone at (978) 531-8555, or by e-mail at abrennan@cast.org, after January 1, 2001.

To learn more about Universal Design for Learning (UDL), please visit the CAST Web site and take a guided tour on UDL at www.cast.org/tours.

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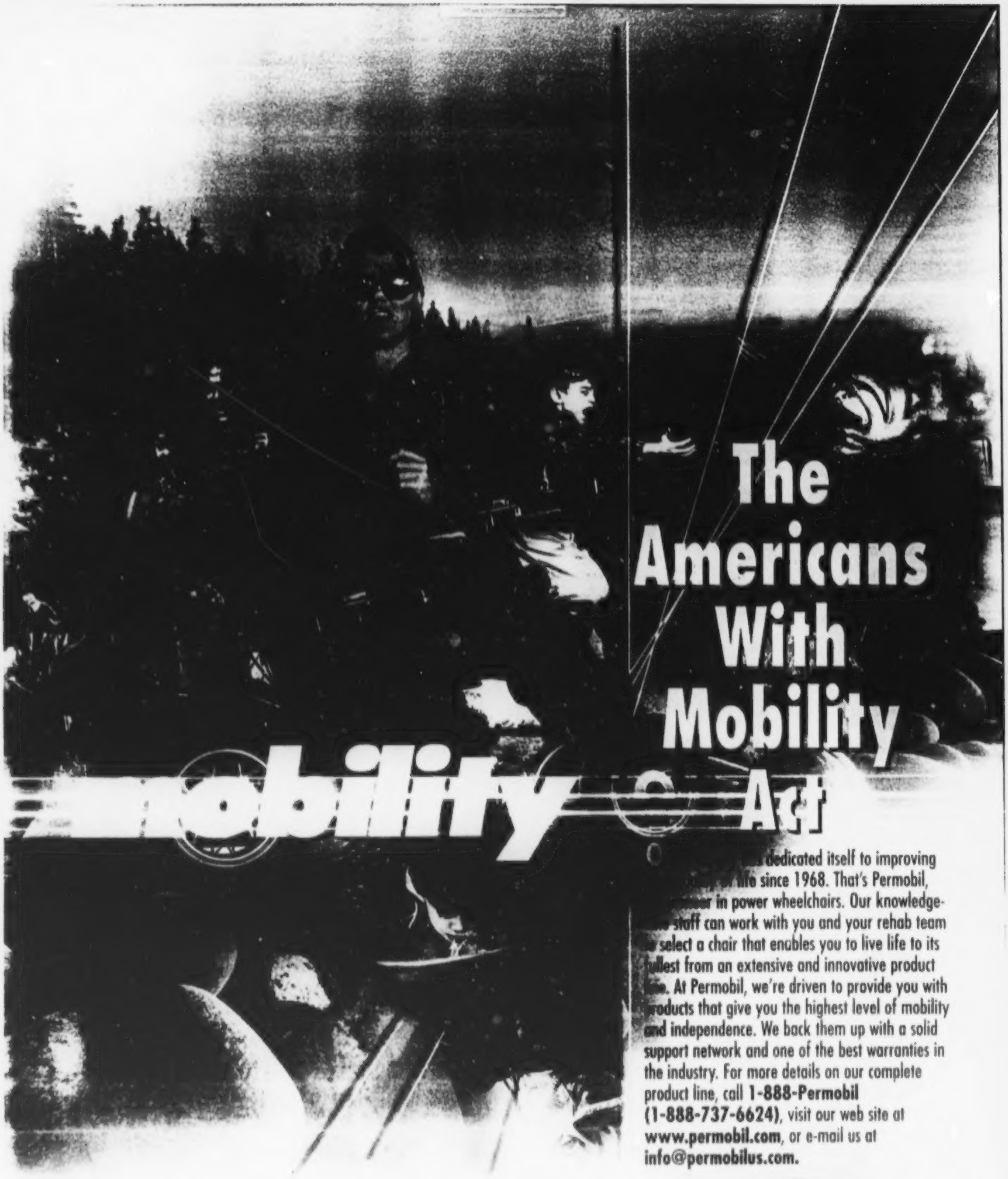

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Circle #5

HEALTHCARE AND TECHNOLOGY

Hand in Hand Toward the Future

BY GALE JURASEK

Advances in technology have always impacted treatments, and within the last decade, they have been breathtaking in their scope. Every day, a breakthrough occurs or a novel treatment is discovered. From scientific theory to noninvasive blood monitoring, here are some of the new, technology-driven advances in healthcare.

Technology is applied science

With the help of computers, two researchers are applying chaos theory to predict some epileptic seizures. Dr. Chris J. Sackellares, a neurologist at the Malcolm Randall Veterans Affairs Medical Center and professor of neurology, neuroscience, and biomedical engineering at the University of Florida, Gainesville, and Dr. Leonard D. Iasemidis, research engineer and assistant professor of electrical and computer engineering at the University of Florida, presented their method of predicting certain types of seizures at the December meeting of the American Epilepsy Society.

The two doctors have used the principles of chaos theory (a mathematical approach used to find patterns in seemingly random events), to recognize changes in brain activity that occur prior to the onset of a seizure. Their first goal was to identify a pre-seizure transition period. They used EEGs to monitor the electrical activity in brains of people with epilepsy. At the end of a 10-day period, they were able to identify a "danger zone" that develops within minutes or hours before a seizure.

The two researchers theorize that a seizure occurs as a natural function of the body to correct anomalies in the neural system. They found that a build-up of organized, harmonious brain signals is predictive of seizure activity. From this finding, they hope to identify a window of opportunity during which a seizure can be prevented. Their work could one day result in implantable devices that monitor brain activity, detect threatening patterns, and delivery therapy.

Getting a better look at fetuses for diagnosis and treatment

While ultrasound remains the most commonly used method of prenatal diagnosis and screening, it often provides only limited information regarding some types of fetal anomalies. Often, anatomical details that affect the prognosis of the fetus are difficult to see using conventional ultrasound methods. The Children's Hospital of Philadelphia has recently started using ultrafast, prenatal magnetic resonance imaging (MRI) as an adjunct to ultrasound for prenatal diagnosis of some disorders.

In the past, traditional MRI scans were limited because of fetal movement. Maternal sedation and fetal immobilization were needed to obtain useful images. The ultrafast MRI uses FDA-approved imaging sequences that take less than one second to perform, decreasing the chance that fetal movement will alter the scan's quality and eliminating the need for maternal sedation.

The ultrafast MRI provides images of fetal organs that can help physicians differentiate between, for example, teratoma and cystic hygroma in neck masses, and allow them to plan for airway management at birth.

Candidates for fetal MRI scanning are usually fetal surgery candidates undergoing evaluation for a potentially correctable congenital anomaly. Prenatal MRI is especially helpful for viewing anatomic definition, verifying a diagnosis, and identifying abnormalities.

The American Academy of Pediatrics Annual Meeting reviewed medical procedures that can now be performed on fetuses. For examples, a fetus infected with parvovirus B19 will develop severe aplastic anemia. Pregnant women who test positive for parvovirus infection can have their fetuses monitored via ultrasound or MRI, and if necessary, the fetus can be treated by *in utero* transfusion. Obstruction of the fetal urethra can be treated by catheter drainage of the fetal bladder, and diaphragmatic hernia can be treated by plugging the fetal trachea, and promoting lung growth.

Pulsed low-intensity ultrasound for healing fractures

Pulsed, low-intensity ultrasound is being considered as a noninvasive treatment for fractures that do not heal properly.

Pulsed low-intensity ultrasound delivers high-frequency acoustical pressure waves through the skin. It can be used as an alternative or in addition to the standard invasive procedures using nails, screws, compression plates, or bone grafts. According to a paper recently presented at the Scientific Program of the American Academy of Orthopaedic Surgeons' Annual Meeting, studies have shown that pulsed, low-intensity ultrasound is capable of accelerating and augmenting healing of fractures in which traditional methods either failed or could not be used.

Noninvasive blood glucose monitors for people with diabetes

According to the National Institutes of Health, several different methods of measuring blood glucose levels noninvasively are

continued on page 38

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2001 technology

Resources

These Web sites contain current information on new technologies in healthcare:

The National Institutes of Health
http://www.nih.gov
The Centers for Disease Control
and Prevention
http://www.cdc.gov
The American Medical Association
http://www.ama-assn.org

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being studied. These include shining an infrared light though a person's forearm or finger and drawing glucose from the interstitial fluid through the skin using a laser beam or extremely small needle.

Although research is ongoing, there are challenges to these methods. The glucose monitor that measures glucose levels using a light beam is a large, tabletop unit. It must be calibrated to each individual using it, and if there is insufficient variation in the person's glucose levels, calibration may not be possible. There are also problems with machine malfunction, and the fact that it is not portable. This device has been approved for use in Europe, but not in the US.

Another system, a wristwatch-type device, fires a laser into the skin, creating a tiny "micropore." Interstitial fluid, which is fluid in the spaces between skin layers, flows into the micropore, and is sampled instead of blood and passed to the same test strip that is used for conventional, finger-stick glucose testing.

An automatic, implantable glucose sensor that can perform precise glucose measurement is currently being researched by a company that also manufactures insulin pumps. This device would be used with their implantable insulin pump, which is currently available in Europe.

"Patient" education

Technology such as the Internet has greatly contributed to educating people about their conditions, treatment options, and healthcare management. Published literature, brochures, and networking whether in person or in cyberspace, have all worked to make today's healthcare recipients extremely knowledgeable. By accessing the wealth of information available, individuals can educate themselves about their health, any medical conditions they have, and treatments they are using. They can use a variety of resources to research the facts about their medical regimens and be more aware of side effects or the risks of noncompliance. (*Because the Internet is not monitored for quality of content, however, users should exercise caution. Good sources of reliable information can be found on Web sites that are affiliated with government organizations or with a medical association or institution.*)

Telemedicine

The world has gotten much smaller due to rapid advances in telecommunications technology. Its impact on healthcare, however, is only beginning to be felt.

The Telemedicine Research Center is a Web site sponsored in part by the National Library of Medicine/National Institutes of Health. In "A Telemedicine Primer," Nancy Brown, MLS, project manager for the Research Center, writes, "Telemedicine may be as simple as two health professionals discussing a case over the phone or as sophisticated as using satellite technology to broadcast a consultation between providers at facilities in two countries, using videoconferencing."

Two different types of technology are involved in telemedicine. The first involves taking a digital image and sending it to another location, where a diagnosis is made, and the information is sent back. Using a form of this method called teleradiology, X-rays, CT scans, or MRI scans can be sent from one location to anywhere in the world. Many radiologists are installing appropriate equipment in their homes so they can have images sent directly to them for diagnosis. Telepathology works in much the same way and involves sending images of pathology slides from one location to another for diagnostic consultation.

The other type of telemedicine technology is two-way interactive television (IATV). This is used when a face-to-face consultation is necessary between an individual and his or her physician. Videoconferencing equipment at both locations allows the consultation to take place. Over the past five years, the technology has decreased in price and complexity, and many programs use desktop videoconferencing systems. *(For an article describing this technology, see "Katie's Amazing Videoconferencing System" EP June 2000).*

The technology provides specialty care where none would be available otherwise. According to Ms. Brown, nearly all specialties are conducive to this method of consultation.

Providing telemedicine can make specialty care available to underserved populations, and alleviate high travel costs. Videoconferencing opens up the possibility for continuing education or training for practitioners who are isolated or in rural areas. Teleconferencing may cut the costs of medical care for those in rural areas.

There are however, some obstacles to telemedicine. Many states will not allow physicians to practice without a license in that state. The Health Care Financing Administration will reimburse for teleradiology and telepathology, but not for speciality consultations for individuals covered by Medicare. Malpractice suits and the lack of "hands on" interaction with patients are also concerns.

Another issue is that the wiring necessary to support telecommunications access is not yet available in many rural areas. However, technology manufacturers and telecommunications companies are working to produce the equipment and bandwidth needed.

Always looking ahead

Countless other advances have been made in healthcare, and more are emerging each year. Technology is being used in extremely innovative ways, and the results, while not always successful, are a tribute to the creativity and persistence of the researchers. In many instances, the techniques they pioneer today will become the standard practice of the future. ■

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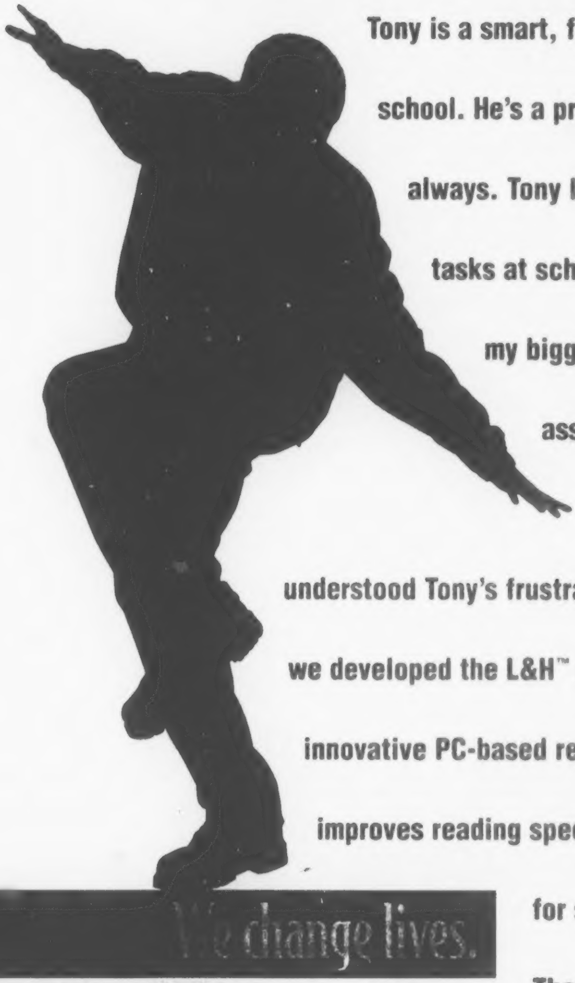
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Circle #59

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Technology and Employment

In today's workplace, assistive devices can enable people with disabilities to do the job!

by Susan Senator

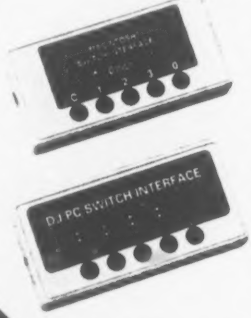
Can technology help a person with a disability get and keep a job? Chances are, there is a technological innovation out there that can. Technology is no longer just the domain of the elite. These days, assistive technology finds its way into a great many jobs for people with special needs. From electric paper folders to talking wristwatches to computers controlled by head movements, there is a full spectrum of technological offerings that can help a person with a disability hold a job. Across the country, in every state, there are transition specialists, vocational rehabilitation agencies, and prevocational counselors who work with students who have disabilities, the school team, and potential employers to make employment happen. There are rehabilitation agencies and rehabilitation engineers who identify abilities in a potential job candidate and who then figure out strategies with employers to help each client with a disability find work.

Technology as simple as a digital watch may be very useful. VibraLite 3™ provides a vibrating alarm that automatically resets when it reaches a preset countdown. By Global Assistive Devices, Inc. (http://www.globalassistive.com. Phone: 954-784-0035).

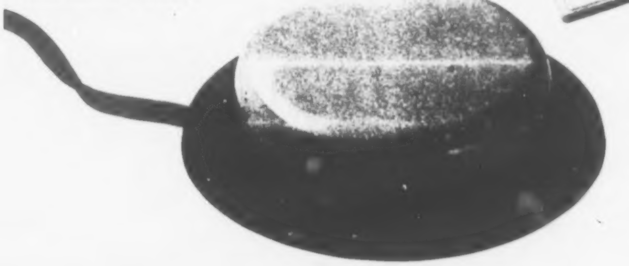
Opening the door

In order to understand how people with disabilities can find employment using technology, one must also understand the obstacles to employment that may exist and how to overcome them. Dr. Ellie Emanuel, associate director of the National Transition Network at the University of Minnesota, says that there are some "69 to 71 percent [of people with disabilities] not being hired in this country...which has to do with attitude and not understanding disability." Part of the misunderstanding feeding these attitudes among employers is the unfounded fear that hiring a person with a disability will result in a substantial cost to their business. The reality is, according to the Job Accommodation Network (JAN), a service of the President's Commission on the Employment of Adults with Disabilities, "two-thirds of all accommodations cost less than $500 and that more than half of employers surveyed report benefits in excess of $5,000."

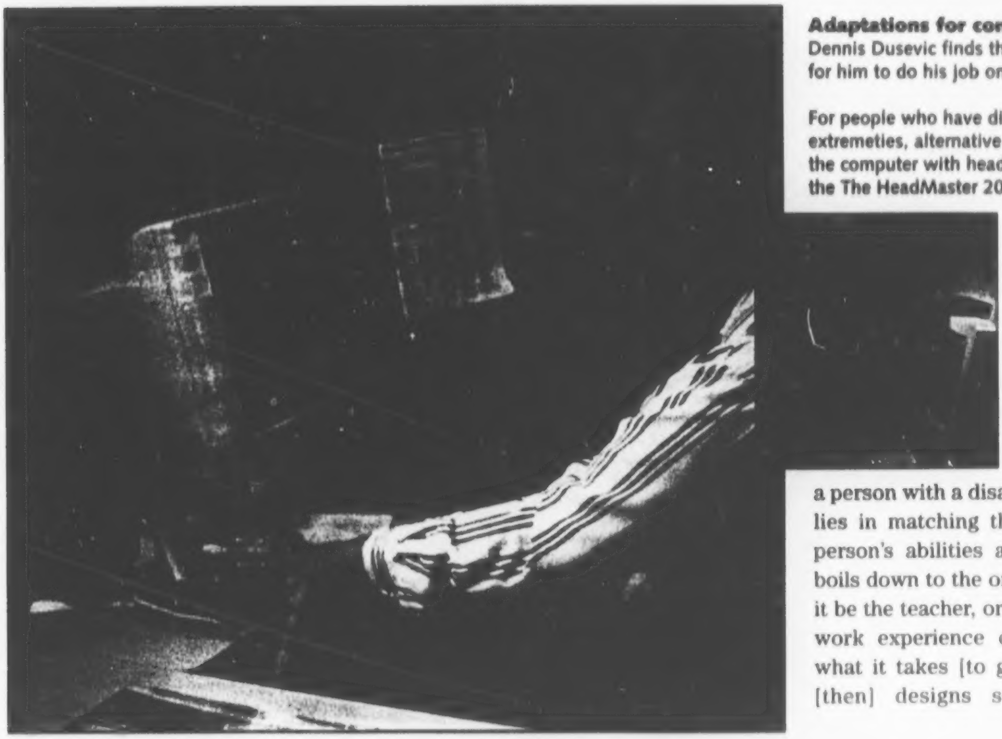
In fact, costs for technical accommodations for employment of people with disabilities can be offset by funding supports in the community. Cost-sharing of technical accommodations and job training is often a possibility, particularly if a school system is involved with the job search. Other incentives to employers exist as well. For example, JAN reports, "employers who hire individuals with mental retardation may be eligible to receive on-the-job training reimbursement from The Arc. Other possible sources of support for employers are their state's rehabilitation agency, or a local Job Training Partnership Act (JTPA) program. Employers may also receive tax credits under the Targeted Jobs Tax Credit provisions of the IRS."



Assistive computer devices, such as the switch interfaces at right, allow users to access the computer using a switch like the one below. For Macintosh (top) and PC (bottom). Both by Don Johnston, Inc. (http://www.donjohnston.com. Phone: 800-999-4660).



Below: the Big Red switch by AbleNet (http://www.ablenetinc.com. Phone: 800-322-0956).



Adaptations for computers. (Left): EP staffer Dennis Dusevic finds that a trackball makes it easier for him to do his job on the computer.

For people who have difficulty moving their upper extremeties, alternative devices enable them to control the computer with head movements. Shown (inset) is the The HeadMaster 2000® by Prentke Romich (http://www.prentrom.com. Phone: (800) 262-1984).

Technology on the job

Once barriers to employment are broken down, how can technology help a person with a disability do a job? The answer lies in matching the right technology to the person's abilities and the job's demands. "It boils down to the one-to-one situation, whether it be the teacher, or the rehab counselor, or the work experience coordinator; who can see what it takes [to get this person a job], and [then] designs something," says Chris

continued on page 43

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Circle #71

JAN: Coming up with technology solutions for employment

As a service of the President's Committee on the Employment of People with Disabilities, the Job Accommodation Network (JAN) is in business, according to its mission, "to assist in the hiring, retraining, retention or advancement of persons with disabilities by providing accommodation information." Whether on their toll-free information line or on their Web site, JAN's services are free of charge and open to anyone. Information seekers can contact JAN to help them find practical strategies for particular situations. JAN's Web site is a gold mine of information for anyone who needs information: people with disabilities, employers, job coaches, etc. Users can search for listings of technology devices, their description, and manufacturer information as well as detailed descriptions of accommodation ideas JAN has come up with for clients with specific disabilities. Among other useful information on the site are: Employment Resources, Disability Legislation, and the new Small Business and Self-Employment Service, which provides information, counseling, and referrals about self-employment and small business ownership opportunities for people with disabilities. If users do not find what they want on the Web site, they can call and ask JAN consultants specific questions (in English or Spanish). JAN consultants who have knowledge of the functional limitations associated with disabilities and have instant access to JAN's comprehensive, current information about accommodation methods, manufactured devices, and strategies. Callers can also request free information from JAN's extensive library in English, French, and Spanish, as well as in Braille and large print, on tape or disk. All calls are kept confidential.

Job Accommodation Network
West Virginia University
PO Box 6080, Morgantown, WV 26506-6080
(800) 526-7234 (Voice/TTY), Web site: http://www.jan.wvu.edu

There is also a Canadian version of JAN, called JANCANA, a service of Human Resources Development Canada/Canadian Council on Rehabilitation and Work. For more information, try their Web site: http://www.ccrw.org.

Here are some of the solutions that JAN has created to enable employees with disabilities to perform their jobs. These and more can be found on their Web site under SOAR, the Searchable Online Accommodation Resource, designed to let users explore various accommodation options for persons with disabilities in the work setting:

- **Computer access**

With more and more computer-centered jobs springing up, the ability to access the computer is critical for would-be employees. Devices to provide access abound. JAN describes a "mouse interface [that] can be activated with a head-mounted device and head movement to steer the cursor, [with] simple switches that can be used for mouse functions," as being excellent options for people with cerebral palsy and limited upper- and lower-body movement. For individuals who can use their feet but have upper-body problems, there is the STEP-ON-IT! Keyboard Control Panel.

Described on the JAN Web site, this tool consists of "three programmable foot switches [that] emulate Ctrl, Alt, and Shift, or any other keystrokes, sequences, or even mouse clicks....The pedals supplement the computer keyboard with three electronic foot switches that take over the operation of selected keystrokes and mouse clicks."

- **Accommodations for visual impairments**

For those with low vision, there are computer screen magnification devices, some of which come with sound cards for supplemental speech, if needed. The JAN Web site includes similar assistive technology devices: "A user can activate keyboard functions with an on-screen keyboard displayed on the computer screen; voice recognition software [that] simply speaks commands to the computer via a special microphone." There are also Braille output devices and speech-output synthesizers so that people with visual impairments can read or hear what is on the screen.

- **Accommodations for hearing impairments**

The assistive technology JAN suggests for those who are deaf or have hearing impairments may be as simple as a telephone amplifier for an individual who needs to use the phone as part of his job. For another client, a bank, the issue was how to help a teller who is deaf communicate with a customer. JAN helped the bank figure out exactly which form of assistive technology would be best: "[We] suggested that teller and customer could communicate using telecommunication devices for the deaf (TDDs)." Though TDDs are most often used on phone lines, JAN knew of another device to connect two units without using a phone line. "With the TDDs, a customer and the teller could communicate by typing on the TDD keyboard."

- **Accommodation ideas for cognitive impairments**

JAN discovered this practical idea to help employees in completing specific tasks in their job: "Self-operated audio (or written) prompt systems can be used by people with cognitive impairments to cue themselves. "The tasks involved in completing a job process can be recorded as step-by-step instructions. The employee can play the tape in a battery-operated personal cassette player with headphones. As an additional support to the employee, JAN recommended demarking the recording to indicate where to stop: "The tape recording contains a bell tone which signals when the machine should be turned off in order to allow time to complete each taskas per the tape recorded direction. At the end of each related group of steps, self-evaluation questions can be inserted. These require the employee to stop the activity and survey what was accomplished, and to ensure that all the steps up to that point had been successfully completed."

continued from page 41

Shoeller, training coordinator for the Social Security Insurance Project in Minnesota, and parent of a successfully employed son with a disability. One man with whom Ms. Shoeller worked started his own business in his home since his fragile health made it difficult for him to work anywhere else. He uses a computer, which he controls by head movements.

> **Technical accommodations are finally catching up to human abilities and are being harnessed to facilitate employment.**

Often the technology that makes things happen for employees with disabilities is as simple as one switch. As a rehabilitation engineer, Dianne Goodwin, ME, of Blue Sky Designs, Inc., often works with students with disabilities, their teachers, employers, and vocational rehabilitation counselors to identify jobs and make them accessible, usually by finding or designing the right adaptive equipment. She recently helped identify a home-based job for a young man who is medically fragile and who has significant cognitive and motor impairment. "We looked at tasks within jobs that he could do with the use of a switch. We met with his occupational therapist, his primary care attendant, his vocational rehab counselor, and his aunt. We identified four tasks he could do with a switch. We then improved access to the switch via a powerlink from AbleNet... and hooked up a paper shredder, electric paper folder, and stapler to that." With this adaptation, Ms. Goodwin's client could activate all the devices that he needed to do his job with his switch.

High-tech and low-tech solutions that work

If a device can help do the job, it does not matter whether it is state-of-the-art or not. In order to accommodate someone with a visual disability, for example, there are many ways to adapt a work environment, ranging from the more dazzling new inventions to innovative uses of commonly used technical devices. Among the high-tech tools out there for individuals who have visual impairments who are in need of computer access, there are screen readers and screen magnifiers (see sidebar for more information). On the lower-tech side, Ms. Goodwin points to the expe-

continued on page 44

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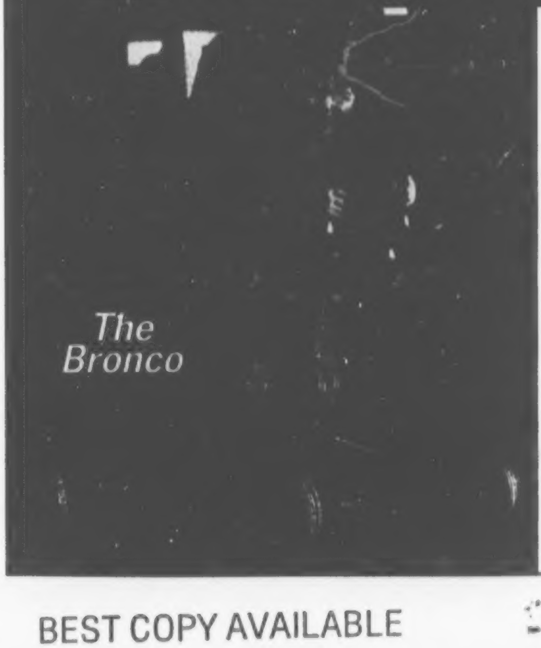

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Circle #46

2001 technology

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rience of one client who was blind, deaf, had cerebral palsy, and used a wheelchair. He was able to get a job stamping boxes with a label designating what was inside. She explains, "The unfolded box was positioned by a jig. The stamper came down in the same place every time; the stamper was on a spring-loaded arm."

Another fairly simple, inexpensive, but very clever technical accommodation is described by Mandy J. Gamble, a human factors consultant with JAN: "An individual with no vision was placed in a switchboard operator position for a large service complex building. The individual needed to be aware of which telephone lines were on hold, in use, or ringing. She was provided with a light probe to assist in determining which console buttons were lit up, blinking and/or steady." The light probe is a sensor that makes a sound whenever it detects a light and the operator passes over the switchboard, listening for any sounds. Ms. Gamble also points out that, "The telephone console was modified to provide the employee audible differentiation for incoming versus internal calls."

Attila Kutashy, employment coordinator for the Parents' Alliance Project in Chicago, attests that often the simplest innovations can help the most. Mr. Kutashy remarks that a simple bungee cord has aided at least six of his clients with disabilities who work for supermarkets, collecting carts. He instructs clients telling them, "Hook up the first cart, then two to five more using the bungee cord to control the carts and group them together." He points out that this method prevents shopping cart accidents and the employers are happy with it. Mr. Kutashy also recommends that clients try wearing digital wristwatches or talking wristwatches if they need help telling time or to remind them to get a job done in a certain amount of time. He says, "This enables them to maintain independence and meet deadlines."

Technology helping the work experience

Problems on the job can always arise, but for an individual who has a disability in which behavior is an issue, stressful situations can be exacerbated. There is a solution, however. For someone who faces that difficulty, a technological device as simple as a pager can be very reassuring. Ms. Goodwin explains that a pager or cell phone can allow an individual to reach out to job support team members. She says, "If they are able to have something in front of them that they can use to call the supervisor or job coach, that can reduce behavior issues."

Technology can also help an individual whose disability may make interpersonal communication difficult. James Stinespring says that an augmentative communication device helps his son, Patrick, who has autism, at his job at a Chicago-area food store. The egg-shaped device clips onto a belt and is capable of sending out eight different messages. By using the communication device, Patrick, 30, does not have to focus too much on social interaction while he does his job bagging groceries. Mr. Stinespring explains, "The important thing is when he works with the public, he needs something for the communication...[because] when he does try to talk, he goes so fast." The augmentative device is a useful innovation that helps keep things smooth for Patrick while he is interacting with his coworkers and the customers.

Something for everyone

Technical accommodations are finally catching up to human abilities and are being harnessed to facilitate employment. The key is hooking up with a vocational rehabilitation counselor who can identify a person's abilities and work with that person's goals. By using the Web (see Web sites below), it is now possible to find out about the latest innovations within seconds and some of the organizations that link up people, accommodations, and employers with funding information. People with disabilities and their families should remember that the law (ADA) is on their side and feel empowered by the significant progress that has taken place in the last ten years. The healthy economy has also created a need for workers. Parents can encourage their children, long before transition to employment is upon them, that they have a place in the workforce. It may not be a perfect world, and may be even less so for our children with special needs; yet there is more within their grasp these days than ever before. We just have to give them the tools to help them do what they can. ■

RESOURCES

JAN (See sidebar): (800) 526-7234
Parents'Alliance Employment Project:
Phone: (630) 495-4345

The President's Committee on the Employment of People with Disabilties Web site:
http://www.pcepd.gov
Project EMPLOY, a project of the PCEPD
Web site: http://www.dol.gov/pcepd/projects/projecte.htm

Community Options, Inc.
A nationally based nonprofit organization providing employment services and appropriate housing for people with disabilities throughout 11 states.
Web site: http://www.comop.org

Just One Break, Inc.
A not-for-profit, no-fee employment and advocacy service for people with disabilities.
Web site: http://www.justonebreak.com

PACER: (612) 827-2966
Web site: http://www.pacer.org/employ
Part of the extensive information on the PACER Web site is the channel called "Employment strategies for youth and adults with disabilities."

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Circle #32

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"You've Got Access"

The "Information Superhighway" still has speed bumps for people with visual and hearing impairments, but technology exists to give everyone a smoother ride.

How does a person with a visual or hearing impairment navigate an Internet that is becoming progressively dependent on graphics and audio?

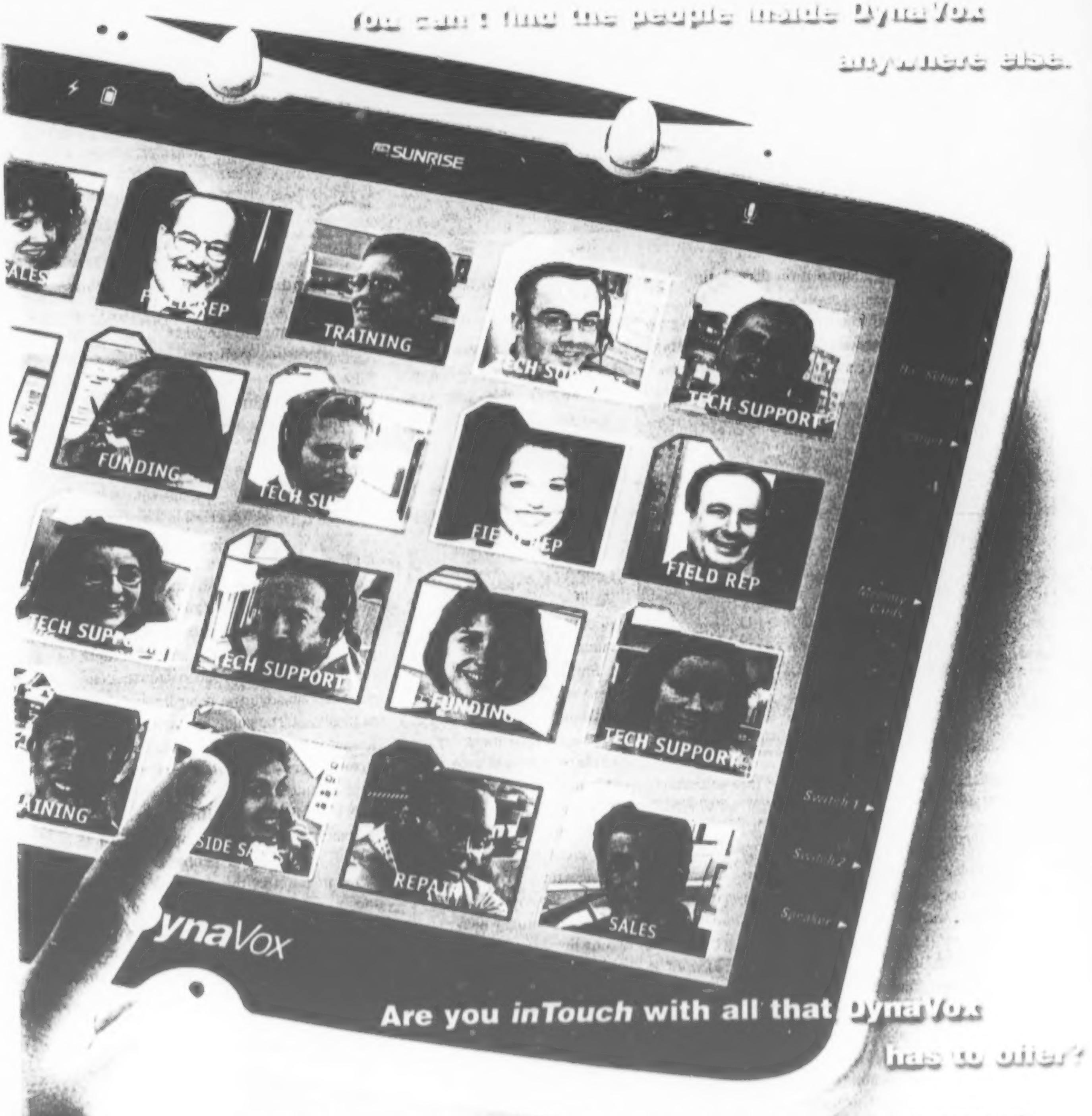
Though the tide is slowly turning, some companies and organizations are still not completely attuned to the needs of people with disabilities and continue to base their Web designs on "bells-and-whistles" technology rather than simpler, more accessible, text-driven technology. For people with visual and hearing impairments, this can present a problem. "High tech," for that population, without the appropriate modifications, often means high barriers to access to the digital age.

Work is being done in many places to counter these technological barriers, however. Advocates have become resourceful in demonstrating that a marriage of new and existing technologies and education on how to implement this union are the keys to achieving full Web access for people with hearing and visual impairments. One such pioneer in this endeavor is WGBH's National Center for Accessible Media (NCAM), a research and development facility that works to make media accessible to underserved populations, including people with disabilities (see box on WBGH next page top).

Based on their successes in bringing accessible media to film and television through open and closed captioning, video description systems, etc., NCAM launched an initiative called the Web Access Project in 1996. Designed to carry the torch ahead to the information age, the Project develops ways to integrate access technology with new Web tools so that users with hearing and visual impairments can take full advantage of the opportunities the Web provides. In addition, NCAM provides Web designers with free information on ways to make their sites accessible. Getting big industry to step up to the plate and help turn technology from foe to friend is another aspect of NCAM's work. As a result of their collaboration with the World Wide Web Consortium (W3C) (see box next page bottom) and some of the computer industry's most influential companies, NCAM has become a force in making accessible Web surfing a reality.

Below is a general look at some of the more prominent current technology that exists for people with hearing and visual impairments who wish to gain access to the Web. *(This list is not exhaustive. Type in*

continued on page 48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DYNAVOX

Circle #79

2001 technology

About WGBH

CPG/WBGH is a nonprofit public broadcasting company in Boston, Massachusetts, that has become a veritable testing facility for ground-breaking research in making television material accessible for people with visual and hearing impairments. To contact WGBH, write: 125 Western Ave. Boston, MA 02134; Phone: (617) 300-5400; Fax (617) 300-1026; or visit their Web site: http://www.wgbh.org

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"visual impairments" or "hearing impairments" on any search engine for links to specific products, or call Geoff Freed, project manager at NCAM, (617) 300-4223, for further information.)

Visual impairments

- Screen readers, which work with speech synthesizers, scan the entire screen and "speak" what they "read," store it on disk, save it into a word-processing application, or prepare it for Braille production.
- Screen enlarger software allows the user with visual impairments to choose an area on the screen, using the cursor or other navigational device, and enlarge it. The user can also specify the size and style of the enlargement.

The Braillex®, by Sighted Electronics, Inc. (see Resources), helps make the Web accessible for people who read Braille.

Hearing impairments

- Multimedia clips (files that are downloadable) can now be made accessible on both PCs and Macs by implementing captioning and voice video-description technology. (Work on making streaming audio/video technology—audio/video that uploads within a Web page and cannot be downloaded—is currently in the developmental stages.)

For Webmasters

- Information for Webmasters on how to incorporate accessible technology into multimedia clips and other technology is available at no charge on the NCAM and W3C Web sites (see Resources).
- Webmasters and Web site designers can now use a generic Web Access Symbol (see picture page 46)—also available on the NCAM Web site free of charge—to indicate that accommodations for people with visual and hearing impairments have been made on particular Web sites.

Chipping away at the walls of ignorance

According to NCAM Project Manager Geoff Freed, up until a few years ago, most of the Web was completely inaccessible to people with visual and hearing impairments. Freed explains that the reason for this has been that many Web site designers have not been made aware of the technology available to them and how they can implement it. The tide is turning, says Freed, however, and Web designers are beginning to catch on. "Awareness is actually better today than it was two or three years ago, and the idea of designing accessible Web sites is something that is becoming more and more prominent." But, says Freed, ensuring continuing compliance to the mission of creating a fully accessible Web means turning action into awareness—theory into practice. "It's one thing for us to educate Web designers on making sites accessible, and it's another thing for them to do it."

The Web Access Initiative (WAI), a W3C project designed to come up with solutions to making the Web accessible for people with all types of disabilities, is designed precisely for this purpose: putting awareness and education into practice. An important component of WAI is the Web Content Accessibility Guidelines. Aimed at Web developers, these guidelines offer step-by-step instructions (see Resources) to produce sites that can be accessed by any user, regardless of the type of disability. The guidelines are also targeted for software producers, showing them ways to make it easier to produce accessible Web content automatically.

WAI Director Judy Brewer explains the outreach of her group's work: "WAI is a unique partnering of people from industry, different parts of the disability community, the accessibility research community, and government, who have come together to look at what the issues are regarding accessibility on the Web, and to develop consensus

About the World Wide Web Consortium (W3C)

The W3C was created to lead the Web to its full potential by developing common protocols that promote its evolution and ensure its interoperability. It is an international industry consortium jointly run by organizations worldwide. Services provided by the Consortium include: a repository of information about the World Wide Web for developers and users, and various prototype and sample applications to demonstrate use of new technology. To date, 458 organizations are Members of the Consortium. For general inquiries, call (617) 253-2613, or log onto their Web site: http://www.w3.org.

solutions for these." According to Brewer, the guidelines are considered by many governments of the world as the definitive resource on how to make a Web site accessible for different types of disabilities. WAI's goal, she says, is to "show that accessible design is not only possible, but is also good design, and well within reach of all Web content publishers."

NCAM's Geoff Freed's solution for action is also centered on going directly to the source. His advice to Web designers is to make the technology that already exists work with them, not against them. "Many more Web site developers are aware of the efforts of WAI, and they're learning that technology is not necessarily a barrier. Though access technology is a couple of steps behind the technology that drives the Web, let's learn how to use the technology that's already in place and not worry about having to design brand new technology."

Interaction between computer and user is the wave of the future. Shown here is a demonstration of an NCAM project to develop a fully interactive, fully accessible, online college course (see NCAM's Web site: http://www.ncam.org). Video description and screen reading technology will allow people with visual impairments access to the course. For people with hearing impairments, captioning technology (in the black box at the bottom of the screen) provides access.

Another incentive for Web designers to produce accessible sites, says Freed, is making them understand that with just a few simple modifications, their sites can be made accessible to ALL users, not just people with disabilities. "We always try to present to Web designers that they are not just designing sites for people with visual or hearing impairments or other disabilities." Freed, who is sighted, offers himself as an example of an average Internet user. "Many nondisabled people use their browsers with the images turned off because of the time it takes to download unnecessary images. So if a designer designs a site with image descriptions or text equivalent links for an image map, for example, I can see the site without having to rely on a graphic. By the same token, someone with blindness, for example, can navigate the site pretty easily with a screen reader." According to Freed, the notion of this universal design concept—versus the idea of making a site accessible for a small group of people—makes better business sense to Web site developers. "It usually perks up their ears," he says.

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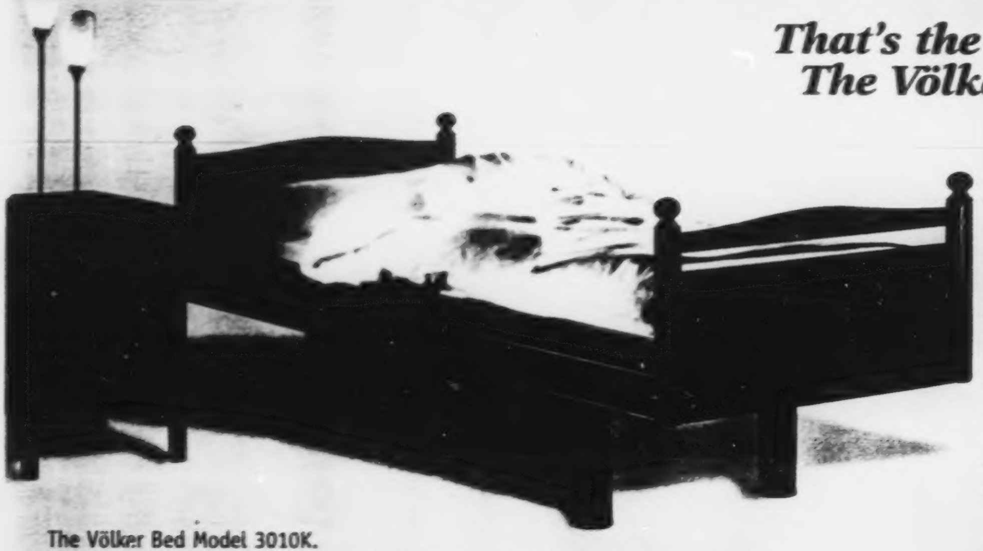

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Brewer, who has a physical disability, remembers the days when research meant pulling heavy journals off book shelves and carting them back and forth. The Internet, however, has offered her online access to an entire library of material, just with a few easy taps on her mouse. "Anywhere that my mind can go, my hands can take me on a keyboard. It has been liberating." But what should a user with disabilities do if, once on the Web, he or she cannot access the information? "Send information to the Webmaster of the site," says Brewer, "and tell him or her about the barriers. Point them to our Web site as a resource area where the people who created that Web site can learn."

The vision of Web accessibility

As the dependence on—and the appeal of—computers and the Internet for research and entertainment continues to soar in today's society, it is imperative that the technology to make the Web accessible keep pace. President Clinton's Digital Divide initiative, which is a plan that partners the US government with technology companies, both big and small, to do their part to help remove the technological barriers, aims to do just that.

Donna Sorkin, the executive director of the Alexander Graham Bell Association for the Deaf and Hard of Hearing, an organization and information center that focuses on pediatric hearing loss and provides ongoing support and advocacy, agrees that the President's initiative is an important step in the right direction. "Access to the Web is obviously important and any person who doesn't have access is at a disadvantage. My son uses the Web all the time to do his homework; there is such a strong dependence it." According to Sorkin, children, both with and without disabilities, have much to gain from full Web access. "If we want our kids to succeed, then we have to provide them with those opportunities." ■

Resources

The National Center for Accessible Media can be reached at:
125 Western Avenue
Boston, MA 02134
Phone: 617-300-3400, voice/TTY
Fax: 617-300-1035
E-mail: ncam@wgbh.org
Web site: http://www.ncam.org

Read the Web Content Accessibility Guidelines at http://www.w3.org/WAI

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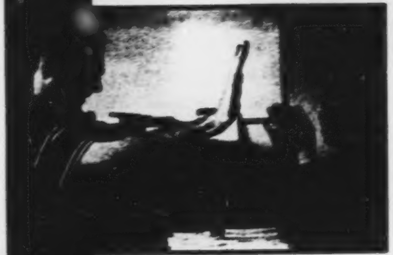

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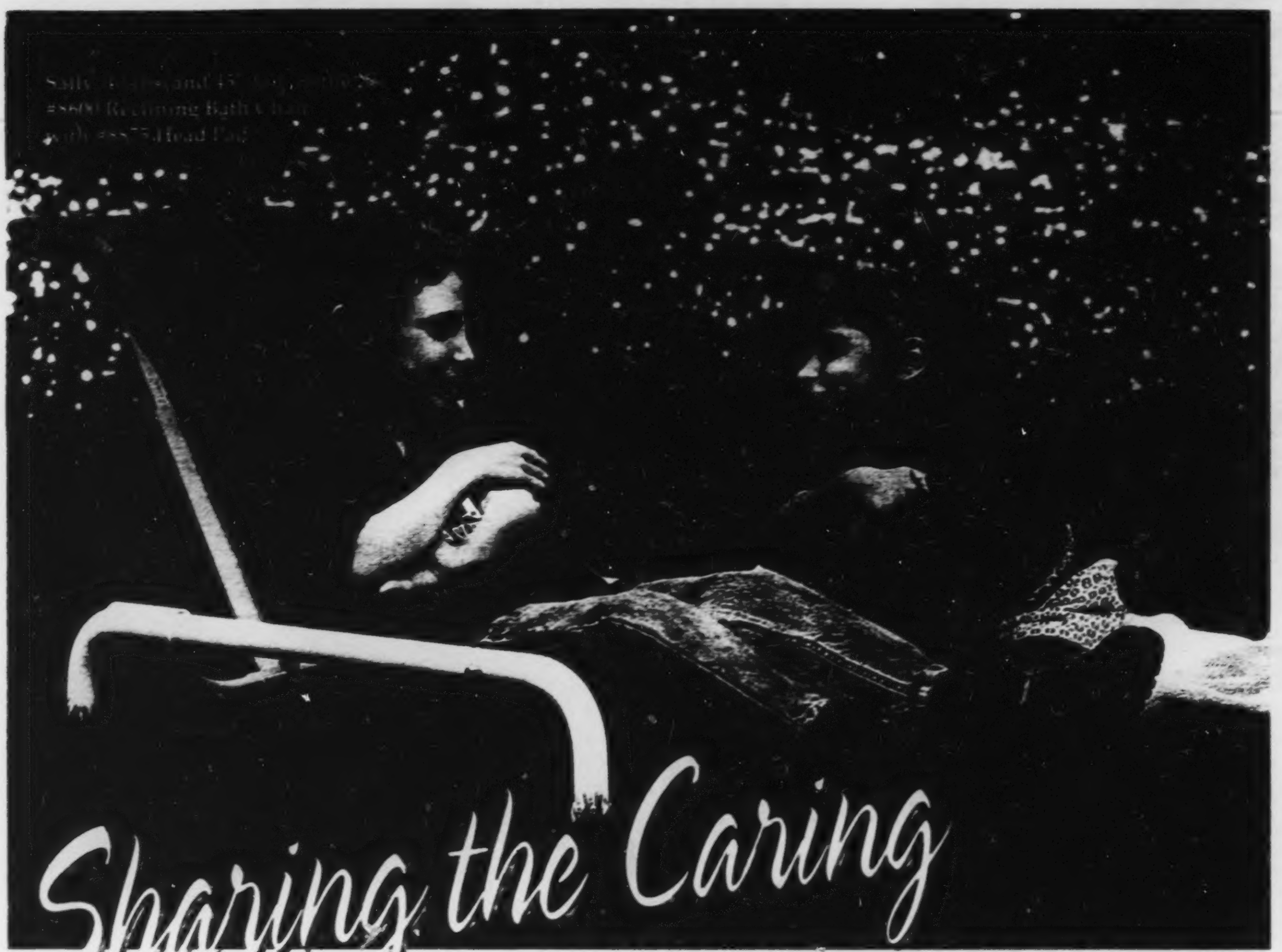

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A Silicon Bullet For Dyslexia:

A New Solution For An Old Problem

This article has been adapted and reprinted with permission of the author from one that first appeared in "Closing The Gap," October / November, 1998.

While assistive technology for accommodating people with "print-disabilities" has been available for years, most students who have dyslexia are still limited to futile attempts at bringing their visual reading up to grade level with remedial training. People who have dyslexia cannot do visual decoding of print at a rate and comfort level so the print language can be understood as it was intended by an author. They may sound out words but they cannot decode language visually at the same high rate that they can decode language orally. Yet, when it comes to learning from print, educators who are not aware of alternative methods continue to tell these students to only use visual reading.

With fourth or fifth grade reading and writing skills, bright students with dyslexia usually graduate from high school passing all subjects, but they are not learning up to their ability and achieving excellence. They are not reading assigned work. They are not taking classes that challenge their high intellect. They are not learning how to communicate their good ideas in writing. While these bright students usually perform well in class discussion and on material that is read aloud or discussed in class, teachers often place them in lower level classes, abbreviate academic requirements, and usually are satisfied when these bright students score as well as low average students on tasks that require visual reading or paper and pencil writing. The most these students can expect is graduation from high school with a recommendation from teachers to keep "sounding out those words" and working on their reading and writing. Unfortunately, they do not leave high school with the reading and writing skills needed to pass college classes.

The educational community is not aware that it has the opportunity to teach students with dyslexia how to make full use of print; therefore, it is not using the technology that will enable these students to "read," "write," and succeed in college programs. Educators mistakenly view this assistive technology as futuristic, extravagant, expensive, and impractical.

One Tennessee school system, however, is proving them wrong. Since 1993, Knox County Schools has been implementing Alternative Methods of Reading and Writing, a comprehensive program employing high- and low-tech solutions to accommodate the daily reading and writing needs of students with severe dyslexia in grades 3 through 12. Despite inadequate visual reading and inadequate handwriting ability, students use print for "reading" and "writing" in regular classes and they excel using print rather than just cope with it. These assistive technology methods and emerging technology will revolutionize the way our schools teach students with dyslexia.

The program: Alternative Methods of Reading and Writing

This accommodation approach has three main goals: (1) students make full use of their intellect in "reading" print and "writing" print; (2) students maximize their ability to use print independently; and (3) students gain access to the same mainstream educational experiences and standards as peers with comparable mental ability.

Reading

Using (1) audio-tape recorded books, (2) text-to-speech voice synthesis with computer, (3) reading assistance, and (4) modified visual reading, students from Knox County are completing all the reading requirements for high school and college classes.

Audio-tape recorded books

Students "read" books recorded on audio tape using their ears rather than their eyes for decoding the print. While using this aural reading method, they follow along in the book visually looking ahead for headings, highlighted words, captions, photos, and other visual information. Using a specially-designed player, they can "read" fast or slowly, quickly skip ahead or back to study the text thoroughly. All textbooks are available from Recording for the Blind and Dyslexic to registered borrowers who only pay $25 per year for all the books they need to borrow. People registered for Library of Congress taped books get access to fiction and nonfiction books at no charge.

Text-to-speech voice synthesis with computer

Using voice syntheses and screen reader software, students "read" words, sentences, and passages by having the computer speak text aloud. By controlling the voice with key

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Using a headset and cassette player, students can "read" books recorded on tape and follow along with the printed version.

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strokes, they quickly "read" anywhere on the screen "reading" from worksheets, dictionaries, encyclopedias, letters, magazines, and newspaper articles, and any other text that can be displayed on a computer screen. As a practical matter, expensive and impractical resources are avoided in favor of easy-to-use ones. For instance, worksheets have only been available when a teacher happens to prepare his worksheets on a computer and can save the file for reading with the screen reader before printing the worksheets for the rest of the class. While use of a print-to-text scanner is possible for getting worksheets onto the computer screen, it has not been practical because of the cost of extra equipment, the labor to prepare documents, and the logistics required to make these scanned documents available to the student on time in a regular class setting. On the other hand, all the text from the Internet can be read aurally using this voice system. With a standard computer and an Internet connection, students gain access to a wealth of literature, research articles, e-mail communications, and many other resources that are free and readily available.

This fact and the rapid improvement in text-to-speech technology is making this approach a "gold mine" for students who need to read aurally. Voice synthesis/screen reading is also an important tool for enabling inadequate readers to write by letting them hear each word as it is typed, read completed sentences, reread previous sentences, and review writing for editing.

Reading assistance

Reading assistance is having another person read text out loud and is thought of as translating the language from visual to oral form. It is not an opportunity to have a partner, tutor, or leader; it is a service where the student with dyslexia directs the assistant on what to read, when to read, to reread, to pause, and to stop. This assistance is often performed by a teacher on tests and other required reading, but can be done by a peer who is informally asked to read a short passage.

Modified visual reading

Modified visual reading requires recognizing the limitations that visual reading places on students with dyslexia, modifying unrealistic expectations, and making better use of visual reading for completing daily tasks. The result is that students (1) make better decisions about when to attempt visual reading and when to employ other methods of reading; (2) make realistic estimates about what can be accomplished using visual reading skills; and (3) perform visual reading in order to cope with reading situations where alternatives are not practical to use. But, when visual reading is used, students with dyslexia modify their expectations by recognizing that (1) visual reading will only give part of the needed information contained in the text, and (2) visual reading will require energy and mental processing which distracts from the intellectual task of processing the meaning of the text.

Writing

With four "writing" methods—(1) dictate and edit procedure; (2) computer-assisted writing; (3) writing assistance; and (4) modified handwriting—students are completing all the writing requirements for high school and college classes.

Dictate and edit procedure

With the above method, oral language is turned into written language by (1) students dictating into a standard dictation device; (2) teachers or assistants typing the dictation into a computer in lower case with no punctuation; (3) students "reading" the text with the screen reader; and (4) students adding capitalization, punctuation, and any other editing changes before print-

RESOURCES

Software
Voice synthesis software
Speech Recognition Software
Free application program with all Macintosh computers
Apple Computer, Inc.
Phone: (800) 800-2775, (800) 767-2775
Web site: http://www.apple.com

Screen reader software
outSPOKEN 3.0 for Windows
outSPOKEN 9 for Mac
Braille Display
Alva Access Group, Inc.
Phone: (888) 318-2582
Web site: http://www.aagi.com

Word processing software
Appleworks
Apple Computer, Inc.
Phone: (800) 800-2775, (800) 767-2775
Web site: http://www.apple.com

Audiotaped textbook services
Taped textbooks
Recording for the Blind and Dyslexic
Phone (800) 221-4792

Entertainment reading on tape
Library for the Blind and Physically Handicapped
For the phone number of the library serving the student's location, contact a local library or call The Library of Congress at (800) 424-8567

Specially adapted cassette player acquired on loan
Library for the Blind and Physically Handicapped
For the phone number of the library serving the student's location, contact a local library or call The Library of Congress at (800) 424-8567

Specially adapted cassette player for school use
Handi-Cassette II Stereo/Player
American Printing House for the Blind
Phone: (800) 223-1839
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2 Track/ 4 Track Cassette Recorder/Player
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ing the work. For now, this procedure is the best way to get students' good oral language into print, but it will be replaced by voice-recognition programs on computers, as soon as computers can accurately and efficiently take dictation from students and print it directly to the screen. The current voice-to-text systems have been found to be impractical for students with dyslexia because they require the student to have sixth grade or above reading and spelling ability and proficiency with complicated computer commands.

Computer-assisted writing

This procedure uses a computer equipped with voice synthesizer/screen reader and conventional software tools to enable students to overcome the reading, spelling, and handwriting barriers that keep them from getting their ideas onto paper. Students (1) type and hear their words pronounced; (2) use a trial and error approach after hearing misspelled words; (3) run the spellcheck and "read" the alternative spelling words from the spell check list using the computer voice; (4) "read" the text from thesaurus and dictionary programs when checking questionable words; and (5) print a draft and ask a proofreader to make a final check. Initially, students are not as fluent using this method, but they are more independent since they correct most of their errors on their own. This accommodation makes use of, reinforces, and complements phonemic awareness, spelling, and other language skills the student has learned in remedial reading and spelling instructional programs. For instance, to use the "trial and error" spelling approach, the student must know the correct phonetic spelling or be able to come close to the correct phonetic spelling. If he or she fails on the first attempt he or she must break the word down into syllables and attempt to spell the syllables using trial and error with the voice feedback, etc., to get a closer-sounding word. Often students who have many phonics skills cannot visually recognize an improved spelling when they make it but can recognize it when they hear the screen reader say the word they spelled. This process leads to a spelling that is close enough to the desired word to get a spell check program to produce the correct standard English spelling for that word.

Writing assistance

Students dictate to a person who writes what the students say. As in the use of Reading Assistance, this is best viewed as translating the language from one form to another. Being effective with this method not only requires ability to concentrate and organize language while dictating, but it also requires social skills, task commitment, and self confidence. While the level of independence in performing this method of writing

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is low, it requires simple technology that is widely available: pencil and paper, a typewriter, or a word processor.

Modified handwriting

Students use their limited handwriting ability to their fullest advantage by (1) making better decisions about when to attempt handwriting and when to employ other methods of writing; (2) making realistic estimates about what can be accomplished using handwriting skills; and (3) accepting less-than-perfect handwriting in order to increase functioning in critical writing situations where alternatives are not practical to use.

Using Alternative Methods of Reading and Writing bright students with dyslexia start "reading" on or above grade level in days. Quickly and effortlessly, they can "read" their favorite novels, magazines, and newspapers as well as all their grade level textbooks. Soon, they are using alternative methods of writing letters and papers. The power and information that is available through print is theirs.

After starting the program, one Knox County student returned from spring break with an attitude of empowerment. She had earlier reported that she felt sad because she was unable to go to the beach, lie in the sun, and read a book like her friends do. This time it was different. She said, "I used the tapes and I lay on the beach and read a novel. I feel like an intellectual." She went on to become president of her class, take the ACT on audio tape, and achieve a high college placement score. Another student, using these methods, recently completed his first year at The University of Tennessee, Chattanooga, making the Dean's List.

Using this program, students with dyslexia are completing high school classes having "read" all the class assignments and "written" all the required papers. They are achieving excellence in high school and they are going on to college so they can become statisticians, lawyers, biologists, teachers, journalists, and intellectuals. ■

Mike Matvy, EdS, NCSP, is the School Psychologist/Assistive Technology Specialist for the Knox County Schools, Knox County, TN

For more information about these or other Alternative Methods of Reading and Writing, contact Mike Matvy at:

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2036 Bethel Ave.
Knoxville, TN 37915-2036,
Telephone: (865) 594-1121 or -1529
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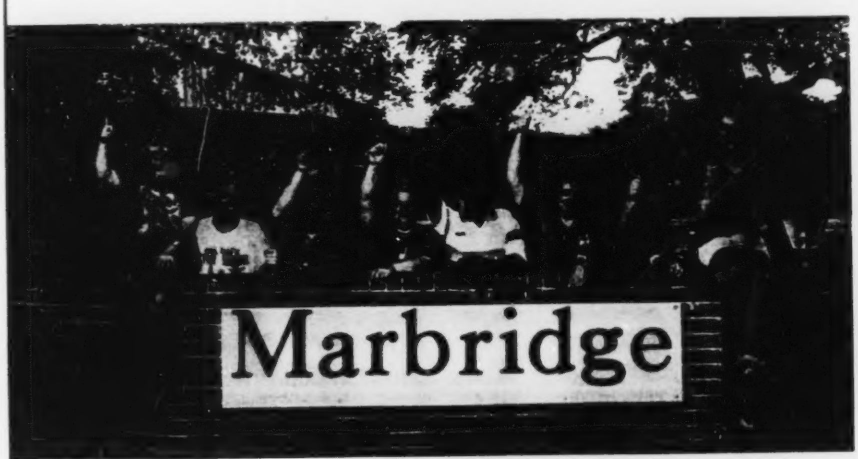

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Grass Roots in Cyberspace

The Internet serves as a launching pad for advocacy

by Janice Janz, Karen Higginbotham, and Kay Marcel

After years of struggling to pay the medical bills associated with their older son's disability, the Crownover family of Lafayette, Louisiana, were looking forward to the implementation of a new state Medicaid program that did not consider parental income in determining eligibility. Less than one month before this program was to come into effect, the legislature announced that it would be cut because of a budget shortfall. Not only the Crownovers, but hundreds of families from around Louisiana were in a state of shock—but not for long. The state had managed to touch the nerve of a very persistent, well-organized, and dedicated group called LaCAN, Louisiana Citizens for Action Now. Advocating for community and family supports for people with severe disabilities, this group was no stranger to struggles with the government. Out of these struggles, however, came some success stories. TEFRA (Tax Equity Fiscal Responsibility Act), better known as the Katie Beckett Amendment, was the program legislators had promised since 1995, and were now willing to eliminate.

Please Save TEFRA

LaCAN organized a rally at the Governor's Inauguration in January 2000. Using the Internet, they were able to assemble quickly and come out in force to demonstrate for TEFRA legislation.

Takin' it to the 'Net

Folks at LaCAN began their advocacy efforts the same day the announcement to cut the program was made. Luckily, they had many strategies that they could dust off and quickly put in place, such as a telephone "tree" (where one person calls two people and they call two people, etc.) and rallies, which were used in previous lobbying efforts. A welcome addition to their strategies this time, though, would be the World Wide Web. Karen Higginbotham, the parent of Alison, a 12-year-old girl with disabilities, called upon creative juices that she never dreamed she had and built the LaCAN Web site, http://www.lacanadvocates.org. She had been learning Web site design for a year, and now she volunteered to use her newly acquired skill as a way to get the message out to people.

How does the Web site help? The greatest advantage of the Web site is its capability to provide information quickly. LaCAN leaders can respond and/or react to updates within a very short period of time. The Web site also eliminates some of the costs of mailing out newsletters and telephoning people (often long distance), though these methods are still used as not everyone has access to a computer.

Another benefit of a Web site is the immense quantity of information that can be posted there. Advocates can quickly become knowledgeable so that they can then go out and spread the message. The information is not only available to existing advocates, but has the potential of attracting others who visit the site to join in the effort. The Statewide Coordinator of LaCAN, Kay Marcel, keeps abreast of

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Still Waiting/Still Advocating

by Anne Crownover

Terry and Anne Crownover with their sons, Ben, 7 (left), and Sam, 4.

My son, Benjamin Robert Crownover, was born on September 13, 1993. He was auburn haired and beautiful. My husband, Terry, and I were ecstatic over having a son and the reality of having a baby. It was 29 hours later that our nightmare began. Ben arrested in the well baby nursery of the hospital. He was resuscitated and brought to the NICU.

We were there for one month. I would sit for hours at a time singing "You Are My Sunshine" and "Itsy Bitsy Spider." When we finally were able to bring Ben home, it was with little knowledge of what was in store for us. We came face-to-face with "the system."

Suddenly I was no longer employed, having to stay home with Ben because of all of his problems. I wanted to be there to do all I could for him and I saw no other way but to hand in my resignation as a legal secretary. Hoping that Ben would improve, we continued on with ours lives. We qualified for one month of assistance. My case worker was new and knew as little about "the system" as did I. Unfortunately, I would come to learn that this lack of information put our family at a definite disadvantage.

Hopes dashed

The next year went by in a complete blur. With no help in sight, we quickly found ourselves hopelessly in debt. Ben needed physical therapy, speech therapy for suck/swallow problems, and occupational therapy. I spent most of my time just tending to that. My husband got a second job teaching scuba diving two semesters a year to help us make ends meet. I started doing legal transcription work at home, getting up at 3 am and squeezing work in when Ben was asleep. It didn't help. Even though we had pretty good primary insurance, we still had enormous amounts of out-of-pocket expenses.

I was told about the Medicaid waiver waiting list and understood that we had been on the list since he was born. In 1996, however, just before Ben turned 3, my case worker informed me that she had just put Ben on the Medicaid waiver waiting list. At the time, I had no clue as to what they meant by it, but now I do. It meant at least another four or five years of waiting for services!

I also heard about the plans for the TEFRA program (see main article). I had little time to investigate the ins and outs of it, but understood that TEFRA would provide for services to us regardless of parental income. It would be a godsend. It was promised by legislators, dangled again and again, but never seemed to come to fruition.

Last year we were informed that the Legislature, after nine long years of investigating and attempting to implement TEFRA, had finally included funding in the budget. Applications were to be in by December 1, 1999. On December 8, our hopes were dashed when the Governor signed a budget cut that removed TEFRA.

A light in the darkness

My husband and I were not surprised for some reason. It had been over six years since Ben came along and we were again faced with no way out. We had exhausted every avenue and every resource available to us. The removal of TEFRA from the budget so angered me that I had to actively become involved in trying to change that decision and get the program implemented. For the last ten months I have tried my best, in what little spare time I have, to raise TEFRA awareness in my area. I found that the best way to accomplish this was through the Internet. I am fortunate to have connected with and met some very good people who are true advocates of our special needs children. These individuals have offered me guidance and I have learned much from them. Among them are Karen Higginbotham and Kay Marcel of LaCAN, who both have children with special needs and who worked diligently at getting legislation passed to serve those who are desperately seeking help. I became a true advocate because of LaCAN. Though LaCAN's advocacy efforts did get the legislature to expand the existing Louisiana Children's Health Insurance Program (LaCHIP), our family does not qualify for coverage. The other new program which was proposed, the Children's Waiver program, is now in the hands of those who will determine if, indeed, it will be implemented. It is possible that the program will cover us, but we may have to opt to continue waiting because of the uncertainty of the provisions of services in the program. Meanwhile, I will continue to advocate as I wait—for my own and other families—in hopes that my efforts will eventually succeed and the state will give us what we need.

Families in our situation put every bit of energy, love, and time into caring for their child with special needs. They have little time to explain to a legislator as to what it is like to have these special children, how difficult it is not only on the child but the families, and they have little energy to put into educating the public on the real importance of this legislation. I feel that we are a silent minority. Our voices aren't heard because we are too busy caring for our special little ones. I know that my journey is far from over with my son Ben, but so far it has not been boring. Every step of the way, I have learned patience and love. I have met some wonderful people and some not so nice people. I have been exhausted emotionally and physically, and I have learned that my family means more to me than anything else on earth, and I will do anything and everything to make us the best that we can be.

Anne Crownover is the mother of two sons, Ben, 7 and Sam, 4. She, her husband Terry, and their sons make their home in Lafayette, LA.

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what is happening in the legislature, posts updates to keep readers informed of the latest events, calls people to action to write letters to legislators and attend committee meetings, and provides needed encouragement. These updates provide great opportunities for brainstorming. One such session yielded an idea that won much-needed public attention for LaCAN.

The state had managed to touch the nerve of a very persistent, well-organized, and dedicated group called LaCAN, Louisiana Citizens for Action Now.

Early in January, Kay noted that the Governor's inauguration would be coming up. This gave one parent the idea for the group to wear their green T-shirts and buttons and hold a rally at the event. The media would be there and LaCAN might have an opportunity to get some needed coverage. The idea sparked a plan that took only a few hours to put in place and e-mail out. Forty to sixty people from throughout the state participated in the rally and caught the attention of the media, legislators, and also Governor Mike Foster. As a result, the Governor paused in his inaugural address to speak to the parents and promised to do what he could for the TEFRA cause.

Another valuable strategy is the Web site guest book. People visiting the Web site are encouraged to make comments on the issue of TEFRA in the "Guest Book." These entries are then sent to state leaders on a monthly basis in order to demonstrate the amount of support the program has gotten from citizens. Often, advocacy groups hear that there are not many people who are concerned about these issues. The Guest Book entries have the power of showing legislators this is not the case. The entries also provide needed encouragement and group cohesion; here it becomes obvious that there are many people who support the efforts of the group.

Recently added are the "Chat Room" and "Bulletin Board," which provide additional ways for people to get involved and share their ideas with others. A time is appointed for people to

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enter the chat room and "talk" with each other on the progress of the TEFRA movement, its problems and its possibilities.

Advocacy means finding more than one way to win

Although LaCAN's advocacy efforts this year did not result in funding to implement TEFRA, the legislature did appropriate $5 million to expand the Louisiana Children's Health Insurance Program (LaCHIP) and begin a new waiver program for children. Public officials estimate that 1,600 of the 4,000 children that would have benefited from TEFRA in the coming year will be served through these two programs. According to the Louisiana Dept. of Health and Hospitals, the implementation of the new waiver program and the expansion of LaCHIP will help reduce the cost of funding TEFRA, which was originally estimated at $9 million in state funds for the first year and $19 million for the fifth year at full implementation. This was accomplished during a fiscal crisis when existing programs were reduced or eliminated. LaCAN advocates will continue to educate elected officials about the ongoing need for TEFRA until the program is funded.

You can learn about LaCAN's work at http://www.lacanadvocates.org, or contact them at:

Louisiana Citizens for Action Now (LaCAN)
713 N. Lewis St.
New Iberia, LA 70560

The effectiveness of an advocacy effort such as this is not always measured by whether the program is funded. It is also measured by how many people's attitudes have been changed, how much people's awareness has been raised, and how many are willing to act and do what is right for the good of all. ■

EDITOR'S NOTE: As of September 30, Louisiana lawmakers discovered that instead of a deficit in their state budget, there may be a potential budget surplus from the 1999-2000 fiscal year that ended June 30. The possible surplus has been estimated to be in the area of $100 million.

Janice Janz is a graduate student at the University of New Orleans. Karen Higginbotham is the Web site Developer for LaCAN. Kay Marcel is the Statewide Coordinator of LaCAN.

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• Circle #25

2001 technology

Professional Credentialing and Assistive Technology

What Parents Need to Know

Michelle L. Lange, OTR, ABDA, ATP

Assistive Technology credentials can help parents choose an AT professional for their child. Above, author and credentialed AT practioner Michelle Lange works with a client.

When I bring my car in for repairs, I assume the mechanic has the training to do the job right. An incorrect assumption may lead to a lot of wasted time and money! When your child needs assistive technology services and equipment, you want the best. But how can you be assured that you are getting qualified help?

Assistive technology services and equipment are provided by a wide variety of people with an even wider variety of educational backgrounds and experience. I have known wheelchair suppliers whose only previous work experience was at the local fast food restaurant before they began telling consumers that they provide seating evaluations! So how do you know who was flipping hamburgers two weeks ago and who is a leader in their field? Assistive Technology Credentials can help.

What is an Assistive Technology Credential?

The Rehabilitation Engineering and Assistive Technology Society of North America (RESNA) has developed the only credential program for service providers in the area of assistive technology. Two separate certifications are offered: Assistive Technology Practioner (ATP) and Assistive Technology Supplier (ATS). ATPs generally provide assistive technology evaluation, training, and education. ATPs often have a background in occupational therapy, physical therapy, speech-language pathology, engineering, or education. Assistive Technology Suppliers are suppliers who are involved in the sale and service of commercially available assistive technology equipment.

The areas of assistive technology addressed in the RESNA program include: positioning, wheeled mobility, computer access, work-site accommodation, augmentative and alternative communication (AAC), and electronic aids to daily living (EADLs)—also known as environmental controls). The examination focuses on appropriate evaluation, training, implementation, service delivery, and ethics.

Several other organizations offer assistive technology courses that provide a certificate of completion. This is very different than the RESNA credentialing process. To earn the RESNA credential, the applicant must meet minimum eligibility requirements (education and experience) to qualify to sit for a written examination. The applicant must then sit for a comprehensive examination. Upon passing this exam, the applicant must agree to abide by the standard of practice, to which all credentialed service providers are held accountable. The candidate is then granted the ATP or ATS credential and may then use these initials after his or her name.

Those people who have passed both examinations are dual certified as both an ATP and an ATS. The ATP or ATS must also meet continuing education requirements to be re-certified, to ensure continued competence. RESNA is currently developing a certification program in rehabilitation engineering and rehabilitation engineering technology. The first exam will be administered in 2001. The cost of the examination is $500. The various courses that provide continuing education units towards re-certification range from free to several hundred dollars. Finally, being re-certified costs an additional $75.

Why should I seek an ATP or ATS to help me with assistive technology?

The certification is designed to increase consumer satisfaction and provide a consumer safeguard. This is particularly important in the area of assistive technology, since the educational backgrounds and level of experience vary so much between both providers and suppliers. While working with an ATP or ATS does not guarantee satisfaction, certification demonstrates the service provider's commitment to the field and baseline foundation knowledge. Just as a certified master plumber is not guaranteed to unclog your drain, he or she should be more competent than your uncle Harry.

*Jimmy** is 13 years old and has Duchenne muscular dystrophy. He went to*

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*Although names have been changed to protect anonymity, these represent actual cases.

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a physical therapist at a local clinic to be evaluated for power mobility, as he was no longer able to push his manual wheelchair by himself. The therapist recommended a scooter. Jimmy was able to try one out in the clinic and did quite well. Unfortunately, within a year, Jimmy was no longer able to drive the scooter. His arms were too weak to hold the handlebars and squeeze the triggers to move the scooter. He needed more supportive seating, which the scooter could not accommodate. When the physical therapist then recommended a power wheelchair, it was denied because the scooter was less than one year old. With the knowledge base and experience required to be certified, an ATP would have known to recommend not only a power wheelchair, but one that could be retrofitted with a power tilt system (to provide pressure relief and comfort as Jimmy's condition worsened) and that could support more than one way of driving (in case he could no longer control a joystick).

How do I find an ATP or ATS in my area?

The RESNA Web site has a list of all ATPs and ATSs by state. You can also contact the RESNA national office (see Resources for information). Not every ATP or ATS works with all types of assistive technology. Some ATSs only work with wheelchairs for adults. Some ATPs may only work with computers and communication devices in the school. Central to the RESNA Standards of Practice is for a service provider to refer to others when a client's need is outside the ATP's or ATS's area of competency. A local credentialed service provider can direct you to the most appropriate person if your needs are outside of his or her practice area.

What if my funding source will not cover services from that person?

Contact your funding source and let them know about the certification process or encourage them to contact RESNA for more information. Using an ATP for evaluation helps to ensure an appropriate equipment recommendation, the first time, thus saving money in the long run for the funding source. Using an ATS to supply the equipment helps to ensure appropriate equipment provision and service.

Sally is 13, and her insurance company paid for three new wheelchair seats in three years. Now Sally's doctor says she needs yet another one. Looking for a way to change the situation, the insurance company referred Sally to an ATP, hoping that this certification would lead to a better and longer-lasting recommendation. A comprehensive evaluation was performed and a new seating system was recommended. This time, however, the seat has already lasted three years and is still meeting Sally's needs with adjustments for growth.*

Are ATP services available in my child's school?

More and more school-based professionals are pursuing the ATP certification. You can check with your school district to see if these services are available. School-based services require not only determining the most appropriate modifications, such as an alternative computer mouse, but also appropriate implementation, working with the entire educational team. An ATP should be aware of the needs of the student and the environment of use, as well as the technology options which may meet the need.

Rosie, 8, has a metabolic disorder which effects her fine motor skills. Rosie is unable to write, and using the standard keyboard and mouse is difficult for her. However, she is quite verbal. Her teacher recommended that the family purchase a voice-recognition program. The family did so and were excited to think how much this would help Rosie in the classroom and at home. As a comprehensive evaluation was not done, no one realized:*

- *the program was not compatible with any of the school's computers;*
- *Rosie could not use the program in the middle of her class without distracting her classmates;*
- *the family needed training in how to use the program; and*
- *Rosie was too young to effectively use this complex system.*

An ATP could have provided an evaluation for appropriate solutions and assisted with implementation.

What happens if I receive poor service from an ATP or ATS?

The certification process is run by the Professional Standards Board (PSB) of RESNA. This Board monitors the entire certification process, including complaints. If you have concerns about the service or equipment you were provided, you can contact the PSB through the RESNA office.

Why should providers or suppliers of assistive technology consider certification?

Certification has many advantages for a provider or supplier of assistive technology. These include referrals, reimbursement, and employment. Many ATPs/ATSs have noted an increase in their referrals as consumers are seeking out qualified services. Some funding sources will only pay for evaluations or training services if these are provided by an ATP. The same is true for equipment. Some funding sources will only purchase from a company who has certified staff. Finally, this certification is an excellent item on a resume, providing external support of your commitment to the field and your mastery of the foundation knowledge needed to provide client-centered service delivery.

Joanne, 15, needed a new seating system. After an evaluation with an ATP (an occupational therapist), a custom-molded system was recommended. Joanne's insurance would only use Supplier A to provide this equipment. Supplier A did not make this particular type of seating system. The therapist contacted the insurance and told them Supplier B made the required system and asked for permission to use this company. The insurance company refused on the basis that this was only the therapist's opinion. The therapist then went on to explain that Supplier B had several ATSs on staff certified by an outside agency as being competent. The insurance used Supplier B.*

I provide wheelchairs. Why should I have to pass a test that covers all those other areas of assistive technology?

Assistive technology has a lot of cross-over.

Persons exploring the use of technology to achieve their goals are whole people, often with multiple functional needs. Service providers need to be aware of the whole picture. Work with a team and refer to others as the needs of the person indicate.

Communication devices can be used as an alternative computer keyboard. The computer can be used to control devices in the environment. A power wheelchair can be interfaced electronically with other assistive technology, so that the same switch used to make a right turn can control scanning on a communication device. That same communication device needs to be mounted properly on the wheelchair. With all this cross-over, anyone providing assistive technology services and equipment needs to at least be familiar with the big picture.

Paul, 17, has cerebral palsy. He uses a power wheelchair, power tilt system, communication device, computer, and electronic aid to daily living (a central control for electronic devices, like TV and radio). However, he can only use four switches. Through interfacing, he can drive with three switches and use the fourth as a reset. The reset switch chooses his operating mode—driving, tilting, or accessing his communication device. His communication device is interfaced to a computer to allow computer access. His communication device is also interfaced to the electronic aid to daily living, allowing him control of his TV and radio. This complicated set-up required competent evaluation by a provider and competent interfacing of the equipment by a supplier. In this case, both were certified.*

Certification is not a guarantee of optimal recommendations, equipment, and implementation. The RESNA credential, like many other voluntary, professional credentials, provides consumers with external, objective assurance that a provider or supplier has met certain requirements in base knowledge and in experience. ■

Michelle L. Lange, OTR, ABDA, ATP, is Clinical Director of the Assistive Technology Clinics of The Children's Hospital of Denver. She is Member at Large of the RESNA Board of Directors. She is the Editor of the Technology Quarterly for the American Occupational Therapy Association.

RESOURCES:

RESNA

1700 North Moore St., Ste. 1540
Arlington, Virginia 22209-1903
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Fax: 703-524-6630
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Web site: http://www.resna.org

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Circle #57

Book helps children understand medical procedure

A new educational tool, "The Adventures with Tomo & Graphy: A Siemens children's book", is being distributed free to all hospitals and healthcare centers with Siemens CT scanners. The book is given to parents and children to read before undergoing a CT exam and simply explains why the procedure is called spiral computed tomography. The storyline ask the children to envision "Tomo" and "Graphy," two characters who work together to make the CT exam run smoothly. It explains in simple terms what kids can expect during this procedure and attempts to alleviate any fears or unanswered questions a child may have. The book and a matching game are available online at http://www.sms.siemens.com. Just click on *CT volume zoom* and then the phrase *computed tomography*.

The adventure
with Tomo
& Graphy

Kids Care Clubs™ launches online volunteer network for families

Kids Care Clubs, a charity which promotes community service projects for children, has announced the launch of FamilyCares, a new online program to help families volunteer together. FamilyCares is the first free online network for families looking for information and meaningful projects they can do as a team to promote values and philanthropy in their children. After registering online, families become FamilyCares network members with immediate access to an online library of detailed projects, ideas, and resources to foster family-based charity. FamilyCares also offers a themed "Project of the Month." Other services offered to FamilyCares members include: Project Central, an online project library; Emergency Alerts: e-mailed or mailed messages to families providing charitable activities that can be done in response to disasters at home and abroad; and Kid's Corner, a place where children can print fun activities such as coloring pages and crossword puzzles, all with a caring message. To find out more about FamilyCares go to http://www.familycares.org.

CALENDAR OF EVENTS

12/1-3 **Abilities Expo**
SAN MATEO COUNTY EXPO CENTER
SAN MATEO, CA
Attendees will learn about the latest in assistive living products and services, as well as answers to important questions concerning insurance coverage, government regulations, and available services.
For more information call (800) 382-3085;
Web site: http://www.abilitiesexpo.com.

12/1-3 **Federation of Families for Children's Mental Health (FFCMH)**
"JUVENILE JUSTICE AND THE MENTAL HEALTH SYSTEM"
RENAISSANCE HOTEL, WASHINGTON, D.C.
Family advocates and national experts will help attendees develop skills to shape local, state, and national children's mental health policy.
For more information call FFCMH at (919) 477-3677, or go to their Web site at http://www.bcfamily.com.

12/1-4 **Zero to Three**
15TH NATIONAL TRAINING INSTITUTE
MARRIOTT WARDMAN PARK HOTEL, WASHINGTON, D.C.
Topics will include early childhood education, early intervention, family support, and prenatal.
For more information call (202) 638-1144;
Web site: http://www.zerotothree.org;
E-mail: 0to3@zerotothree.org.

12/7-10 **The 16th Annual Division for Early Childhood (DEC) Conference**
"EARLY CHILDHOOD IN THE MILLENNIUM: PARTNERSHIPS & PRACTICES FOR THE FUTURE
ALBUQUERQUE CONVENTION CENTER, ALBUQUERQUE, NM
Topics will include assessment and information gathering methods, intervention/instructional strategies, and cultural diversity and international issues.
For more information call DEC at (410) 269-6801, or go to their Web site at http://www.dec-sped.org.

12/6-9 **TASH**
"MOVING THE EDGE"
FOUNTAINBLEAU HILTON RESORT, MIAMI BEACH, FL
Disability advocates gather to share technology, strategies, information and much more, with a goal of full inclusion for people with disabilities.
For more information contact TASH at (410) 828-8274 x 107; TDD: (410) 828-1306; E-mail: info@tash.org; or their Web site: http://www.tash.org.

VISIT OUR WEB SITE, WWW.EPARENT.COM, FOR UP-TO-DATE INFORMATION ON THE WORLD CONGRESS AND EXPOSITION ON DISABILITIES—THIS MONTH!

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Circle #61

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New Online e-zine for teenagers

Disability Central, Inc., has announced the publication of @ctive Teen Beyond all Barriers. This e-zine (online magazine) is written by and for teens with disabilities. @ctive Teen will provide many opportunities for teens to get involved. A chat room is available for teens to start support groups and for writers to conduct forums for their articles. Volunteer chat room hosts are being recruited and contributing writers are welcome to submit their work for publication. @ctive Teen can be found on the Web at a link from http://www.disabilitycentral.com. Disability Central is a new site created by people with disabilities for people with disabilities, and has plans to grow. Any ideas for Internet programs, services, or products that can be showcased at Disability Central can be sent to Dr. Stein vie e-mail at DocStein@aol.com.

Fall 2000 Consumer Information Catalog

The free Fall 2000 Consumer Information Catalog, published by the Federal Consumer Information Center (FCIC), is now available. Consumers can order many free and low cost booklets on a variety of topics using the catalog. Some of the booklets include information on learning disabilities, fun and safe play for your child, and answers to questions about the ADA. To obtain a copy of the catalog call (888) 8 PUEBLO (878-3256); Fax: (719) 948-9724; or visit the FCIC Web site at http://www.pueblo.gsa.gov. The site contains full text of all publications listed in the catalog as well as consumer news and links to other helpful Web sites.

The ArcLink.org Connects People with Developmental Disabilities with Providers

The ArcLink Inc. announced the launch of TheArcLink.org, the nation's first site designed to empower individuals and their families to make sound choices about services based on accurate and up-to-date information. The sites serves as a resource for assessing needs, understanding the application and eligibility process and searching for providers who can meet their needs. Nationwide, users are able to use the site to find and share information and contact other self-advocates, family members, and professionals. This Web site is the the first to provide customized, specific information on the various sources of assistance available to individuals with disabilities and their families. Some of the resources available on the site include: information on national and state service systems and funding available for people with disabilities, a provider search that allows users to locate specific service providers (from orthodontists to piano teachers), information on state and local Arc chapters, news, and links. For more information on this service call (877) 431-8532; (812) 332-2168 or go to their Web site at http://www.TheArcLink.org.

CORRECTION: In our August Children's Page, we erroneously defined Rett syndrome (RS) as a degenerative genetic disorder that leads to mental retardation. In fact, RS is classified as a neurodevelopmental disorder in which mental intelligence is difficult to measure. For more information on RS, contact the International Rett Syndrome Association at (800) 818-7388, or log onto their Web site at http://www.rettsyndrome.org. We also misidentified the author, Jesse Matros, as Jesse Ferencz. We sincerely apologize for these errors and regret any inconvenience this may have caused.

Product Recall Information

The U.S. Consumer Product Safety Commission protects the public from unreasonable risk of injury or death from 15,000 types of consumer products under the the agency's jurisdiction. To report a dangerous product or product-related injury, and for information on CPSC's fax-on-demand service, call their hotline at (800) 638-2772 or CPSC's teletypewriter at (800) 638-8270. Consumers can obtain this release and recall information at CPSC's Web site: http://www.cpsc.gov. Consumers can report product hazards via e-mail at info@cpsc. gov.

In cooperation with the US Consumer Product Safety Commission (CPSC), Rashti & Rashti Inc., of New York, NY, is voluntarily recalling about 12,700 pacifier clips. The metal clip and the small rivet that attaches the clip to a small stuffed animal on the pacifier holder can easily break apart, posing a choking hazard to babies. The recalled Magic Years® Novelty Pacifier Buddy Clips were sold individually, also as part of a set with a matching bib. Consumers should take the pacifier clips away from babies immediately and call Rashti & Rashti at (800) 472-7484 for information on receiving a refund.

In cooperation with the US Consumer Product Safety Commission (CPSC), Kinderkids™, of Lawrence, KS, is voluntarily recalling about 18,000 inflatable playrings. Babies sit inside the playring, which is used as an activity center and looks like a pool float. This product poses the risk of suffocation. Consumers should stop using the playrings immediately and contact Kinderkids for information on how to receive a refund: (888) 433-6251.

In cooperation with the CPSC, the Maya Group Inc., of Garden City, CA, is voluntarily recalling about 20,000 toy bars for repair. The toy bar attaches to car seats and strollers and has removable toys. One of the toys, a car, can break, posing a choking hazard. The toy bars being recalled are the Tiny Love Super Car-Bar. Consumers should remove the toy car from the toy bar immediately and call Maya for a free replacement toy at (888) 521-2202. Consumers also can write to Customer Affairs, The Maya Group Inc./Tiny Love, 12622 Monarch St., Garden Grove, CA 92841.

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1… 2 buckle my shoe
Age 3 – a new kidney

Phil and Kathleen Berardo knew before their son Thomas was born that he had kidney disease. At age 1, one of his kidneys was completely nonfunctional and the other only worked at 20 percent capacity – enough to sustain a small baby, but not a growing boy. Thomas would eventually need a kidney transplant.

In the early days, Kathleen recalls being unable to even say the word "transplant" without crying. But under the guidance of pediatric nephrologists Lewis Reisman, M.D., and Isabel Roberti, M.D., Ph.D., of the Division of Pediatric Nephrology and Transplantation at **Saint Barnabas Medical Center** – the first program of its kind in New Jersey – Thomas received loving, specialized care. In time, Kathleen learned that knowledge is power. And the more she and her husband learned about living kidney donation, the more confident they felt.

In September 1999, Phil donated a kidney to his son Thomas. The surgery was performed by Stuart Geffner, M.D., Director of Transplant Surgery at **Saint Barnabas Medical Center**, who is credited with having performed the first laparoscopic kidney removal in New Jersey, in conjunction with Jeffrey Stock, M.D., Co-director of the Division of Pediatric Urology.

With two other sons to care for, Kathleen is thankful to family and friends who have helped make a challenging time more manageable. "Despite all the effort involved in caring for a chronically ill child, we would not change a thing. Thomas is our inspiration. He is such an amazing child. We are blessed that he has been entrusted to our care."

Thomas and children like him with kidney disease are the inspiration behind Saint Barnabas' commitment to providing quality renal care for people of all ages.

The Saint Barnabas Renal Transplant Centers, among the largest in the country in affiliation with Newark Beth Israel Medical Center, have pioneered medical breakthroughs in New Jersey, among them, the first living donor kidney transplant, the first pediatric transplant program, and the first laparoscopic kidney donation.

At Saint Barnabas Medical Center, we're proud to treat more patients than any other hospital in New Jersey.

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Circle #83

book notes

by Joy Liebeskind

At this time of year, with school and other activities starting, many of us struggle with ways to explain our children's issues to their friends, classmates, and siblings. Children's books featuring characters dealing with issues similar to those our own children face are a great way to open up the topic, share the information with them in a fun way, and allow them to ask any questions they may have.

Surprisingly, many books are available today in which one of the characters has a disability. Some of these books have been specifically written to explain a disability, while others may just include a child with a disability as a character. Here are a few suggestions to start your collection.

Blueberry Eyes

by Monica Driscoll Beatty
illustrated by Peg Michel
Health Press.
Available through the
EP Library (800) 535-1910
Code: HP1001YP
Cost: $8.95 plus shipping and handling

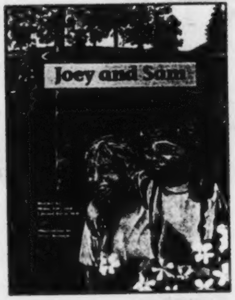
BLUEBERRY EYES
written by monica driscoll beatty
illustrated by peg michel

Meeghan, age 7, tells us "the story" of her eyes—from her first pair of glasses at the age of 4 months, to eye muscle surgery at age 7. She shares the experience of wearing an eye patch, getting bifocals,being the only one in her class with glasses, and preparing for her first surgery. In a charming way, she explains her fears of surgery, of going back to school, and finally her pride in showing off her beautiful blue eyes in her bifocal glasses.

Once your children meet Meeghan, they will be able to think of their own eye doctor and glasses in a very positive way.

Joey and Sam

by Illana Katz
& Edward Ritvo,MD
Illustrated by Franz
Borowitz Real Life Storybooks
Northridge, CA.
Available through the
EP Library (800) 535-1910
Code: RL8003AM
Cost: $16.95 plus shipping and handling



It is not easy to be the sibling of a child with autism. For two brothers close in age, accepting their differences can often be a struggle. As the story begins, Joey is frustrated and embarrassed by many of his brother Sam's actions. He does not know how to explain Sam to his friends at school. They all see the extra help and therapy Sam gets. Joey wishes he were like all the other kids.

At a school show, Sam reads a poem and dances with his class. Joey and his friends suddenly realize how much Sam can do. The book can open a discussion on accepting people as they are as well as helping children to realize we are all different, and that it can be a good thing.

Where's Chimpy?

by Berniece Rabe
photos by Diane Schmidt;
Albert Whitman & Co.,
Niles Illinois.
Available through the
EP Library (800) 535-1910
Code: AW115DS
Cost: $5.95 plus shipping and handling

WHERE'S CHIMPY?

Misty is a delightful little girl who has Down syndrome. We meet her at bedtime, as her dad is trying to tuck her in bed for a story. But she cannot find Chimpy, her toy monkey. So Misty and Dad retrace her steps of the day, collecting up her toys as they search for Chimpy. Misty is like any other little girl as she shares the highlights of her day with Dad.

A day in Misty's life is an easy way to explain disabilities in general to children, teaching them how much alike all children are to each other.

Joy Liebeskind is the Director of the PATH Parent Resource Library, which is part of the Connecticut statewide parent network.

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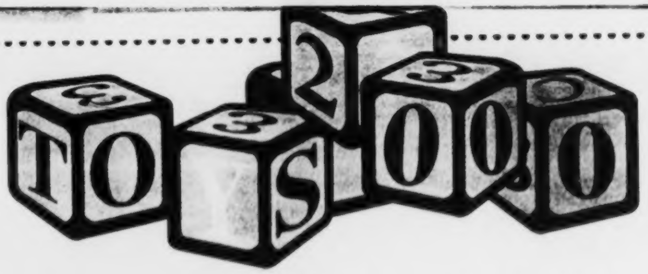
TOY AND PLAYTHING IDEAS



by Don Lytle, PhD, and Rebecca Lytle, PhD

In today's world, toys and the processes and culture surrounding them are significantly different than in the past. Many modern and commercialized playthings are not disability-friendly. This is a bit ironic because the history of many children's toys and games has related to individuals with disabilities. Jigsaw puzzles, first called "dissected" puzzles, were educational tools often cut to suit the age and ability of children. They were considered ideal for "convalescents." First introduced in 1922 in order to ease children's fears of visiting a doctor, the toy doctor bag continues to be a staple of children's playthings. Like so many others who had polio in the 1940s, Eleanor Abbott spent long hours recuperating. She created games and activities for children who also had polio. One of her inventions is the ever-popular board game, "Candy Land." The following list of classic toy and plaything ideas will provide hours of accessible, enjoyable play time activities. Most can be found at variety stores.

Silly Putty (made by Binney & Smith, Inc.) can be flattened out and pressed against comic book pages or the Sunday funnies so the pictures are transferred to the Silly Putty. It can also be used to strengthen fingers, hand or foot grip, and improve dexterity.

Balloons are one of the simplest toys ever invented. They are inexpensive and can be used for a variety of games and activities such as hitting it off of body parts, playing volleyball with a partner, kicking and chasing, stomping, and batting. They are also fun to blow up and slowly let the air out to make a squealing noise. One of our children's favorite activities is to blow the balloon up and then let go and watch it fly crazily. Large round 8 to 12 inch balloons are best. They are easier to blow up and float better than odd shaped balloons. **Safety warning:** Balloons can be a choking hazard. Always be sure to keep balloons and small pieces of broken balloons away from children who might put things in their mouths. (Editor's Note: For children with latex allergies, latex-free balloons are available. Contact the Latex Allergy News; telephone: (860) 482-6869; Web site: http://www.latexallergyhelp.com for more information.)

Blocks are a great toy for creativity and fine motor development. Children can stack or create all kinds of things from castles to barnyards to towers. Sometimes the most fun is knocking the construction down after it is built. Some children might like an adult to help them build a structure so they can have the joy of knocking it over. It could be a giant monster or dangerous animal. What an empowering action for the child! Children who use a wheelchair can do this with their footrest if the tower is on the floor or with their hands if playing on a table.

Bubbles are another wonderful inexpensive toy that no home should be without. Bubbles are a wonderful way to help children with visual tracking skills and eye-hand coordination as well as breath control support and trunk stability. Children can blow, chase, catch, kick, and pop in all sorts of ways.

Recipe for homemade bubbles:

Four tablespoons of glycerin (available at most drug stores)
Four tablespoons of liquid dish detergent
One quart of water

Heat until warm, stirring occasionally. Remove and allow to cool. Make your own bubble wands with straws, plastic toy pipes, bendable, lightweight wire from craft stores, or even a ring from a plastic six-pack holder.

Empty boxes can be used to make puppet theatres, cars, or doll houses. Larger boxes such as those from refrigerators or televisions can be used to make playhouses or forts. Children can paint them to create whatever they want. This can become a fun family project on a weekend afternoon. In our house, we have helped our children construct playhouses, boats, space ships, and more with old boxes. The possibilities are endless.

Kites have been a favorite activity for children–and adults –since recorded history. After getting the kite off the ground, flying requires minimal effort and can be very relaxing.

Sand is a wonderful medium for tactile stimulation. Large amounts of sand are conducive to shoveling, building, and digging activities. Children can also have a great time with smaller amounts—pouring and measuring and painting sand pictures.

Velcro paddle and ball can be found in most toy stores. Playing with them can be a fun activity that helps develop eye-hand coordination and for children with minimal grip, the paddles allow for a high rate of success.

Yo-yos can assist in developing fine motor skills and upper body dexterity. It can be a great toy for children that may have limited lower body mobility. ■

Don Lytle, PhD (alias "Dr. Play"), is a Professor of Physical Education at California State University, Chico, and is a former President of the Association for the Study of Play.

Rebecca Lytle, PhD, is an Adapted Physical Education Specialist, and currently coordinates the Adapted Physical Activity Program at California State University, Chico.

The Lytles are married and parents of two children.

Have a Happy Holiday

Preparing your child with autism for the changes in routine that occur during the Holidays can help keep everyone's spirits bright

by Cindy Alspach

Holidays are an especially stressful time for everyone, and even more so for children with autism. Think about it: Daily routines are disrupted by school breaks, special events, and visits from friends and relatives. Unusual foods and drinks are cooked and served. Families may travel to visit faraway relatives and friends. Even our homes are transformed as we rearrange things to accommodate holiday decorations and guests. No wonder parents report that some of their child's most challenging behavior occurs during the holidays!

There are things we can do to make the season easier for our kids. Here are a few tips I have found helpful:

1 **Evaluate your plans.** Write a list of all your specific holiday plans. Think about your child's daily routine and be sure you have written down everything you intend to do that deviates from it. Since every child with autism has his own unique perspective, you will have to decide which activities will be tolerable for your child and which will upset her. Put a check by every event that might be troublesome. This will give you a good idea of where and when to expect challenging behavior.

Read over your checked items and think about just how important each activity is for your family to have an enjoyable holiday. If you conclude that an activity is not really all that necessary, consider skipping it. Sometimes the things we think we must do are not really worth the turmoil they generate. It is possible to have a perfectly delightful Christmas WITHOUT visiting the department store Santa.

2 **Decorate with care.** If you are planning lots of elaborate decorations in your home, let your child examine and even handle the decorations (if safe) before you put them up. Explain what the items are and where you intend to display them. Have your child help you decorate, and, if he wants, let him choose a decoration for his bedroom. Not only will this help her integrate the rest of the changes in the house, it will serve as a daily reminder, immediately upon waking, that it is the holiday season and things are going to be a little different.

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> **If you are planning lots of elaborate decorations in your home, let your child examine and even handle the decorations (if safe) before you put them up.**

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Some children adapt better if decorating is done gradually (adding one or two items each day), while others prefer to have the whole transformation in one fell swoop. Keep in mind, any sensory problems your child has when choosing decorations, such as musical items and rapidly blinking lights, can often be more frightening than fun.

Create a routine. As much as possible, try to establish a daily routine for vacation days from school. While it is tempting (and sometimes inevitable) to let your child stay up late or sleep in on vacation days, you will have a much easier time in January if you stick to his usual bed and rising times.

After a few days off from school, kids can have a tough time fighting off boredom. The more structured activities you can provide during the day the better. If your child tends to regress or lose ground over school vacations, you can schedule some daily study time or create fun activities which correlate to whatever schoolwork she was doing before vacation.

Prepare, prepare, prepare. Are you expecting a visit from faraway and seldom-seen friends or relatives? Inform your visitors before they arrive about your child's disability. Be very specific about your child's sensitivities, fears, and behaviors. If Great-Aunt Minnie from Peshtigo is a cheek-pincher, you will save everybody a lot of grief by telling her beforehand that your child cannot abide anyone touching his face.

If your visitor is someone your child has seen before, help him remember her by reminiscing about her last visit. Show videos or photographs of the visitor, or bring up special gifts your child may have received from him or her. If your child has never met the visitors, show photos or videos and explain who they are. Mark the day of the visit in the calendar and count down daily with your child ("Three more days until Uncle Ned comes to visit!").

On the day of the visit, let your child know that if the visit becomes too loud or overwhelming, he has permission to escape. Arrange a calming activity in his room or another room in the house that will be quiet and free of visitors. During the visit, watch your child for signs that he is becoming overloaded. At the first cue, take her out of the crowd and let her jump, spin, eat something crunchy, rock, swing—whatever sensory stimulation she needs to calm and regroup. Because you have already properly advised your guests about your child's autism, no explanations or apologies are necessary.

A word of caution: Sometimes well-meaning people will want to discuss your child's autism or ask questions about his behavior, and they may try to do so as if your child is not there, e.g., "Does he always do that?" or "How well does he do in school?" Unless your child is older and is comfortable discussing her disorder, this kind of question can generate extreme anxiety for your child. You can turn this off quickly by bringing your child into the conversation. You may say to your child, "You're a very good student, aren't you?" or tell your curious guest, "Why don't you ask him yourself?" Most people will not cross-examine a child, so conversation turns seamlessly elsewhere. For those few clods who persist, you can politely say, "I'll be happy to mail you some information about this and talk with you about it at some other time." And then change the subject to something else that includes your child.

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When *you* are the visitor. Ideal and successful holiday visits for a child with autism will be in familiar homes with small crowds. They will also be short (three hours or less). Unfortunately, the ideal is not the typical.

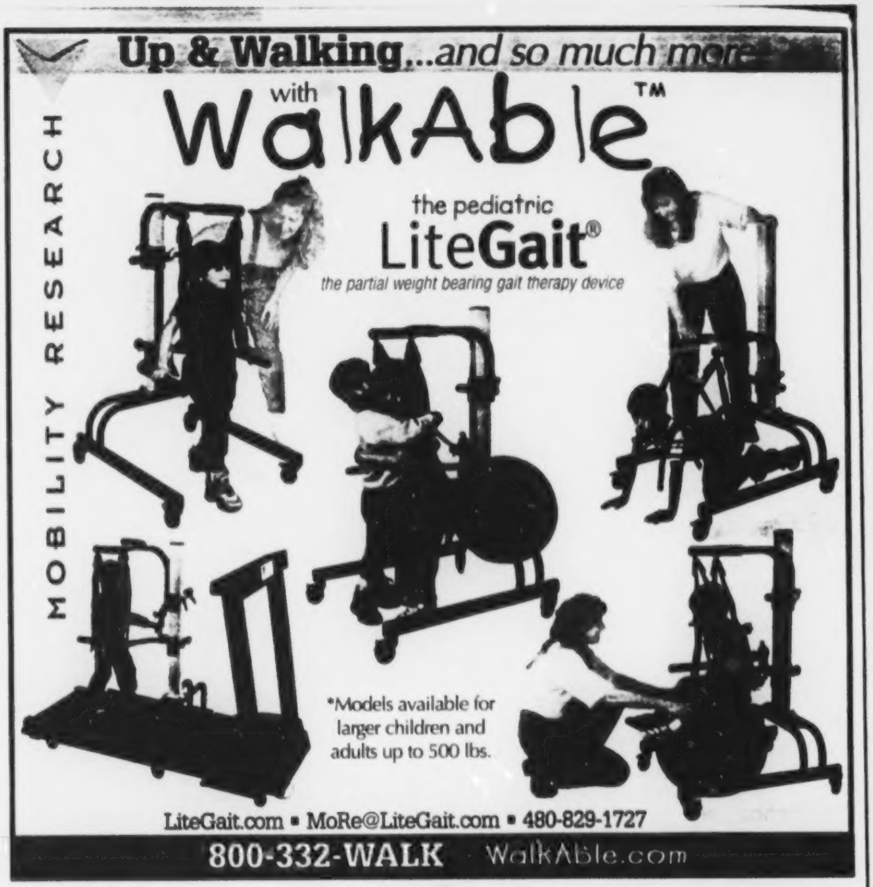
Discuss your travel plans in detail with your child. Let him know where, when, and for how long you will be visiting, and that you will return home. For long rides on a bus, train, or plane, bring along a familiar and much-loved toy or doll (and a spare in case it gets lost), and plenty of books, puzzles, games, etc. For kids with auditory sensitivities who can tolerate headphones, a personal stereo or cassette player will block out external noise and entertain simultaneously.

Again, photos and videos of the people and places you will be visiting are helpful. Older children may enjoy plotting and following your route on a map. Plan for plenty of breaks away from the crowd, both while traveling and during the visit. Keep plenty of crunchy and chewy foods on hand, and stake out "quiet spaces" wherever you can find them.

Leftovers. Once the celebrations have passed, use the remaining vacation days to work back into the school day schedule. The post-holiday time will be a stressful transition, too. Whichever approach to decorating worked for your child (gradual or sudden) should be employed for UNdecorating as well. Be sure to explain, especially to younger children, that the holidays are over, but will return again next year.

Despite the best preparations, unpredictable things will arise and challenging behavior will happen. Whether it is a major tantrum or a minor outburst of weirdness, all you can do is relax and take it in stride. And look at it positively—now you know what NOT to do next year! ■

Cindy Alspach is the mother of a son with autism. Along with two other moms, she founded the Upper Peninsula Autism Parents Support and Action Group in Marquette, MI.



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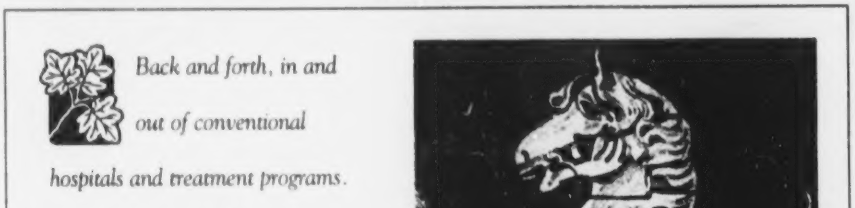

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Everything's A-OK

by Kerry Pianoforte

Tarah Schaeffer may look familiar to you—that's because for the past eight years she has appeared in a reoccurring role on the children's television show Sesame Street. This outgoing 15-year-old balances going to school, appearing on the show, and dealing with her disability. Tarah has osteogenesis imperfecta type 3, a disorder characterized by bones that break easily—often with little or no apparent cause. She has sustained more than 100 bone breaks, and according to her mom, Kathy, has had, "too many surgeries to count." She has used a wheelchair since early childhood. Yet, despite these setbacks, she has an amazingly positive attitude and has accomplished much in her life.

Above: Tarah surrounded by her sisters Samantha (left) and Amanda (right).

Right: Tarah and Ernie share a scene. Below: In her early days on the set of Sesame Street.

OPPORTUNITY KNOCKS

Tarah and her family first learned that Sesame Street was looking to add a character who had a disability to its cast when the coach of Tarah's wheelchair sports team suggested that she try out for the part. Though she had no acting experience, Tarah went to the audition and won the role. With the support of her family and her mother as chauffeur, Tarah has made the trip from her home in Pennsylvania into New York City, where the show is taped. She has met many interesting people on the set including Joe Pesci and Diane Sawyer. Tarah reports that everyone on the set is great. "All the people are so nice and it's very homey there. It made me feel included." Tarah mother thinks that being on the show has been an extremely positive experience for her daughter. "It is good for her self esteem. She always knew the things that she couldn't do, she is reminded of that every single day. This is something that she could do. It also lets other children know that it is okay to be different."

Because of Tarah's condition, special care must be taken in all that she does. Bumpy car rides, crowds, rough playing, or even an overly rambunctious dog can prove very dangerous for her. Despite this, Tarah's family, which includes dad, Glenn, and sisters, Samantha, 11, and Amanda, 9, try not to shelter her and allow her to cautiously try new things. The family has two dogs, Molly and Jenny. The large labrador retrievers have been trained to be extra gentle with Tarah. Kathy recalls the advice she received from an orthopedist when Tarah was first diagnosed with OI. He said, "You are going to have to risk things if you want her to grow on the inside." Kathy adds, "Not that you want her to get hurt at all, but you want her to able to experience things like going to the beach and sitting in the sand and feeling the water. We feel that the only way she will grow both intellectually and spiritually is being able to experience these things. It's better to risk something and gain a whole new perspective then not to try at all."

JUST ONE OF THE KIDS

Just as most sisters do, Tarah, Samantha, and Amanda spend lots of time together. Tarah says, "We play video games, t-ball, or we will

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just hang out in the neighborhood. I have a powerchair and I will drive around and see all the neighbors." Though her parents and siblings don't treat her as special, they make adaptations to include her and allow her to live her life as normally as possible. For example, when she played jump rope she would be the rope holder; or when the they played baseball she would use a t-ball. "We even made sure that it happened in school, that they included her. They did not want her to have gym at all, but we wanted them to let her have a little bit of gym, but have the activities modified so that Tarah could get involved. In kickball she would use a nerf ball and have somebody push her around the bases," says Kathy.

Fitting in with her high school peers has proved to be a challenge to Tarah. Because of her size she feels that her classmates tend to "baby" her. She also realizes that people stare at her because she is in a wheelchair. She tries to combat this by talking to and getting to know others. Tarah explains, "Sometimes, when they're doing that, I will go over and say hi. Sometimes the little kids will ask questions." Tarah will take this opportunity to educate people about her disease. "I don't look at (the situation) like 'stop staring at me'. I try to be positive about it."

IT'S ALL IN THE WAY YOU LOOK AT IT

Kathy says that she has always tried to teach her daughter "to look for the positive in any situation, instead of thinking about all the negatives." Mother and daughter put this philosophy to the test recently when Tarah had yet another surgery to correct her knee. Together they went over the "pros" and "cons" of having surgery. They discussed the negative aspects, such as not being able to swim and being stuck in the cast for the summer. However, Tarah's mother is quick to point out the positives: "She didn't have to take her finals and she would have a normal knee when it was done."

Taping for her segments on this season's Sesame Street will be in the fall. When asked about her acting plans after Sesame Street, Tarah replies, "whatever comes next." Currently, she is making plans for college with her parents and high school guidance counselor. Kathy offers this advice to parents who are afraid to let their child who has special needs try something new: "Let children experience things to the best of their abilities. We can't teach them to be independent if we continue to let them be dependent on us. That's our goal for Tarah, to teach her to be independent. She won't need us forever and she will be able to do things on her own." Tarah wants to study journalism and is considering going away to college. She is on a waiting list for a canine companion, which she hopes will give her more independence. Tarah hopes that by appearing on Sesame Street she will send the message to other people "that people with disabilities aren't any different emotionally, even though they may look different." ■

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Empowering Informed Consumers of Genetics Technologies and Services

The Genetic Alliance: "Clear, up-to-date, and culturally sensitive information enables families and their healthcare providers to make meaningful and appropriate decisions."

by Sharon Terry, MA, and Mary Davidson, MSW

Members of the Chromosome 18 Registry and Research Society gather for a group photo at the Genetic Alliance 1998 membership training conference.

We stand at the brink of a new age brought about by fast-emerging genetics discoveries. The intense hype and fragile hope of this age plays to an eager, but vulnerable audience. Over coffee in our kitchens and listening to the evening news in our living rooms, we struggle to make sense out of all of this. The translation of new research to healthcare and the fight to ensure access will require all our thoughtful and informed reflection and concentrated energy.

As we live the day-to-day experience of parenting exceptional children, we are keenly aware of the changes in the world around us. Does the increase in genetics information mean new treatments or services for our children? How real are these new discoveries?

Alliance members attend an educational seminar.

The apparent promise of genetics—new services and technologies—encourages us to hope and work in new ways. We need high quality, accessible information, the crux of making informed decisions about treatments and services.

Advocating for children, adults, and families, the Genetic Alliance is the largest international genetics coalition encompassing both consumer (individuals with genetic conditions, their family members, and caregivers) and health professional organizations. These groups work together at the Alliance to enhance the lives of those impacted by genetics. Serving over 300 lay advocacy groups, the Alliance gives voice to millions of people living with genetic disorders, both common and rare.

Emerging genetics

We read about completion of the human genome sequencing and the surge in availability of genetic tests. The role of parents is shifting along with these revolutionary changes. With accelerating advances in genetics, we must sort out the meanings and long-range implications of the discoveries by finding relevant information. Access to quality information, expert counsel, and compassionate support can significantly mitigate the impact of a diagnosis, empower people to take appropriate action and, ultimately, help realize the promise of genetics knowledge to prevent disease and promote health and quality of life.

The Genetic Alliance is committed to designing and implementing innovative strategies to empower consumers and lay advocacy organizations to meet escalating demands for understandable, accurate, and up-to-date genetics information resources. Newly acquired genetics understanding is shifting the public's scientific worldview and role expectations as healthcare consumers.

Ultimately the promise of genetics services is to improve healthcare. But in this time of transition, while many of the technologies are still largely theoretical, informed community dialogue is the first step toward advancing genetics research and applications to improved healthcare. Genetics organizations, both public and private, must collaborate to produce culturally competent, community-based resources. The Genetic Alliance offers clear and credible information to individuals and families and their healthcare providers. At the same time, the Alliance provides a needed forum for community dialogue and empowerment.

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The objectives

The Alliance advances these objectives:

- All ethnocultural, disease, and disability communities should collaborate in dialogue, discussions, and consensus-building solutions to challenges posed by genetics.
- Consumers, health professionals, and industry leaders should participate in public policy decision-making.
- Communities should make informed and autonomous decisions about utilization of genetic services and technologies.
- Healthcare professionals should understand the unique needs and resources of individuals and families who live with genetic conditions.
- Lay advocacy groups should receive the technical assistance essential to evolving into mature, informed, and effective support, advocacy, and research organizations.

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www.hmsschool.org

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The Information Resource Network (InfoNet) is the lifeblood of the Genetic Alliance, providing a critical grassroots connection to those whose lives are impacted by genetics. The InfoNet is the hub of phone, e-mail, and postal Helpline requests and is staffed by full-time genetic counselors, interns, and genetic counseling graduate students. InfoNet callers receive referrals to information sources, support groups, genetics centers, hospitals, clinical research studies, and community organizations. A searchable database of more than 600 resource organizations sits on the Alliance Web site (www.geneticalliance.org), providing direct links to condition-specific information for the public and healthcare professionals.

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Lay advocacy organizations enlist the voices and engage the hearts of individuals and families who yearn for solutions, relief, services, treatments, and comfort. Under the umbrella of the Genetic Alliance, these groups are empowered to face the smallest challenges and emboldened to overcome even more global and seemingly impossible obstacles.

Lay advocacy groups make a difference in the lives of millions of individuals and families. Most of all, they have offered hope forged from the stark reality of collective experience and the power and potential of people working together.

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Circle #18

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Horsin' Around

The New York Therapeutic Riding Center and Equestria™ provides therapy and fun for people with disabilities

by Kerry Pianoforte

Off a busy, noisy mid-Manhattan street, the quiet oasis of a riding stable is the setting for some special bonding. Amid the muted sounds of hooves padding on dirt and the occasional light laughter of children, parents gather in the waiting area and watch proudly as their children mount and ride horses. They are then escorted around a ring and practice basic riding techniques such as trotting and verbal commands. The children smile and wave to their parents as they ride by. The children are part of the New York Therapeutic Riding Center's Equestria™ program, a year-round therapeutic horseback riding class. The program is open to children and adults with physical, mental, and emotional disabilities. Participants in the program have a variety of disabilities including cerebral palsy, spina bifida, sensory integration disorder, and autism. Some participants are sponsored by local organizations and the program can provide partial scholarships.

The New York Therapeutic Riding Center and the Equestria™ program are members of the North American Riding for the Handicapped Association (NARHA). Founded in 1969, NARHA now has more than 600 therapeutic riding programs throughout the United States and Canada. According to Michael Kaufman, director of education at NARHA, "One of the amazing benefits of therapeutic horseback riding is that it can serve as a treatment tool for people of all ages and with various levels of physical disabilities." The Center's Program Director, Richard Brodie, further explains the benefits of horseback therapy, "One of the things that happens with the therapeutic riding is that it gives a person a tremendous boost to their self confidence. Being able to control this big animal is something that gives people with disabilities a great boost to their sense of themselves." Richard adds that in addition, horseback therapy improves balance and posture, develops coordination, mobilizes trunk and pelvis, strengthens muscles, improves attention span, promotes independence, and improves social integration.

PHOTO CREDIT STEPHANIE CIMINO

PHOTO CREDIT STEPHANIE CIMINO

Clockwise from top: Nahjela, 8, takes the reins and rides Paydirt. Tommy, 5, works on his upper body strength with a volunteer and Honeybun. Julia, 5, mounts her horse, Casco, with the help of her therapist and volunteers. All three children have cerebral palsy.

The program is run by a therapeutic riding instructor, a therapist, and volunteers who act as "spotters" leading the horses and supporting the children. Therapeutic riding instructors are trained and certified by the American Riding Instructor Certification Program (ARICP), are members of NARHA, and have experience teaching riding to people with disabilities. The physical and occupational therapists also have a strong background in horseback riding. Although many of the volunteers have had previous experience with horses, they are given special training. According to Richard, "We like to always get instructors who are skilled both as riding instructors, as well as therapeutic riding instructors. We want to teach kids to ride as well as to use riding to help them at the therapeutic level." Mixing fun with

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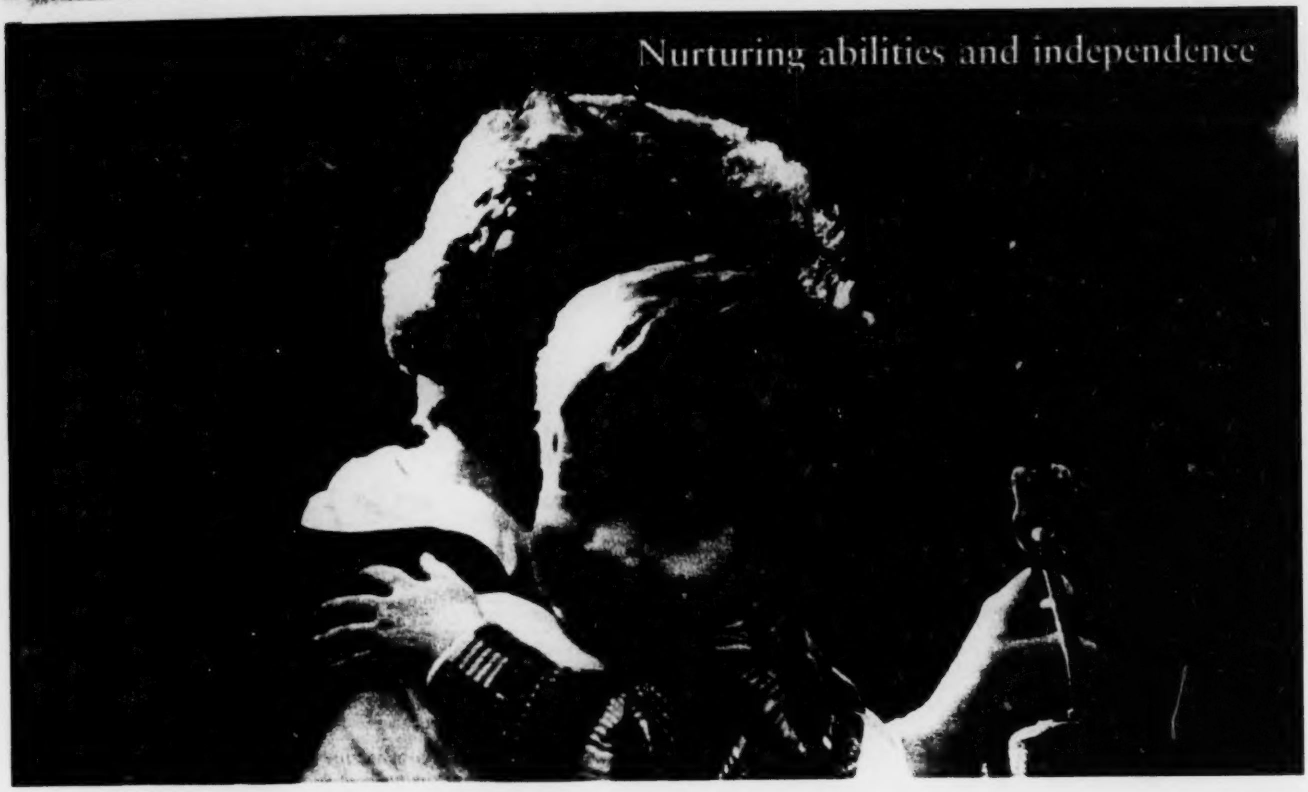

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Matthew, 4, practices using verbal commands to develop his speech skills.

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beneficial treatments is what therapeutic horseback riding is all about.

Therapeutic riding students progress at varying rates, depending on the degree of their disability, energy level, motivation, and how often they practice. Students first learn the basics of riding. Then they begin to focus on how the riding experience can be used to promote therapy goals. Students practice passing a ball back and forth with their volunteers to promote better balance and eye-hand coordination. They learn and use verbal commands such as "walk on" to command the horse to trot. This helps to improve verbal skills and confidence. Students also use physical commands, such as using the reins and their legs, to control the horse. Students brush and groom their horse after a ride, which is a good relaxation technique for both horse and student.

Mounting up for fun

Children wear safety helmets and the instructor, therapist, and volunteers all assist the student in mounting the horse. If the student uses a wheelchair, cane, or crutches, a mounting ramp is used. After the student is on the horse, the instructor and volunteers check to be sure that the student's body is properly positioned: the children's body must be aligned with the horse; the feet are in the stirrups; and they are holding the reins correctly. During the class, the riding student is accompanied by a volunteer leadwalker who guides the horse with a lead rope and by two volunteer sidewalkers who walk alongside the horse, assisting the rider to maintain balance and proper alignment on the horse.

Correct positioning on the horse is key to a good ride for both horses and students to enjoy the natural rhythm and motion. According to experts, the reason therapeutic horseback riding helps children with disabilities is that the horse's body actually exercises the child's muscles in a unique way. The movement of the horse's back moves the body of the child and encourages the child to use his or her own trunk and legs for balance and support. Therapeutic horseback riding instructor Anna Boylan says this therapy is especially helpful for children with disabilities because, "they are working and doing exercises, but they are having a good time and they don't realize they are working out." She adds, "It is good for them. Sometimes it's the only thing that gets them out of their wheelchair. Horses are kind and seem to understand, the children just love to look at them and touch them."

Parents have noticed results as well. Matthew, 4, had a cerebral bleed when he was born and has sensory integration disorder and speech delay. His mother says, "This has helped him in many ways: in his speech, it has helped his confidence, and it's helping him get more upper body tone. It's really been a wonderful experience for him." She observed that after his first session, Matthew was motivated to speak about his experience. "Before, he didn't have complete sentences, and now his sentences are starting to fill in."

John brought his daughter, Julia, who has cerebral palsy, to the 10-week program at the recommendation of her orthopedic surgeon. Julia, 5, says the program "is fun." John feels that after only four sessions, it is

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too soon to see much improvement. However, he notes, "I can see each time she rides, she's riding better. This is something that is not a quick fix." Julia's riding instructor, Anna, agrees, "When she first started she was barely able to sit up and now she can sit up by herself. It happened gradually, but she has made amazing improvements."

PHOTO CREDIT STEPHANIE [illegible]

Lacey, 8, enjoys a ride on Honeybun. Lacey has muscular dystrophy.

Health benefits, for both body and spirit, have always been associated with horseback riding. But beyond that, there has always been an unexplained bond between humans and horses—one based on trust and understanding. As the children in Equestria and other therapeutic riding programs can attest, those natural benefits can make a world of difference. ■

For more information on therapeutic horseback riding or to locate the nearest center contact:

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Photo by Joyce Ravid

The Vogel family (from left to right): Doug, Rachel, Gretchen, and Nadine. Nadine has advocated tirelessly for her daughters, and is the founder of SNAP (Special Needs Advocate for Parents), a nationwide organization.

A Recipe For Life

by Nadine Vogel

My family + My career = My life. That's who I am. A mixture of strong family experiences and values combined with a rewarding career that blends personal and professional objectives. Everyone has their own recipe for a satisfying life, and some may think that my mixture has had its share of lumps, but in the end, my recipe is hearty and fulfilling, and I wouldn't change a thing. Here's my personal list of ingredients:

My family

I'm a 36-year-old mother of two beautiful daughters, Gretchen and Rachel. Both of my girls were born with special needs.

When our first daughter Gretchen was born, the doctors told my husband Doug and I that we shouldn't expect her to live longer than 48 hours. She was born with an undiagnosed neuromuscular disorder that left her unable to swallow on her own. Gretchen was fed, and continues to be fed, through a tube in her stomach. In addition, she suffers from left side orthopedic issues and speech problems. As a result, we had to deal with lots of equipment: mechanical suction machines, oxygen, various monitors, and special seating devices, to name a few. Add to that a few surgeries and doctor/specialist visits too numerous to count, and it seemed insurmountable. But with the odds stacked against her, Gretchen has not only survived but thankfully thrived. Nine years later, Gretchen is cognitively fine and attends a regular fourth grade class at a public school.

The scenario was quite different with our second daughter, Rachel. Rachel was diagnosed at birth with Wolf Parkinson White Syndrome (WPW), a condition that affects the conduction of the heart. At any time, Rachel's heart could speed up to 300 beats per minute, potentially causing congestive heart failure. Rachel also has an irregular heart beat and a few other minor things which are closely monitored. Now 1 year old, her condition continues to be watched very closely and is currently controlled by medication. Surgery is planned down the road a bit.

Two children with very different special needs. They are also two little girls with distinct personalities. Not long after Gretchen's birth, her pediatrician gave me some advice which I took to heart and am very thankful for. What he said was, "Treat your baby like a baby, not like a medical problem. Look beyond her physical limitations because you don't know what's inside that just can't come out yet." Not only did we need to address our daughters' physical needs but their emotional well-being could not be ignored. The toughest part is distinguishing the lines between being your child's nurse, therapist, psychologist, caseworker, and just being a mom.

In Gretchen's case, because she was so physically impaired as a baby, we were given home therapy programs to follow daily. These sessions were always tough on all of us. Here I was, a new mom, deliberately doing things to my child that I knew hurt her and were making her cry. One session in particular stands out in my mind. Not long after Gretchen began to talk, she looked at me during one of her therapy sessions and through her tears said, "Stop that. You're my mommy, not my therapist." How those words hurt.

I immediately realized that there was a line I had crossed. I could not be Gretchen's professional therapist and her mommy. It was necessary to have a therapist come to the house, and even better, to reinforce some of the therapy during playtime, but it was absolutely not OK to take away that special mother/daughter bond of trust and comfort—even in the spirit of helping Gretchen get better. With each role I played, I learned where that invisible line

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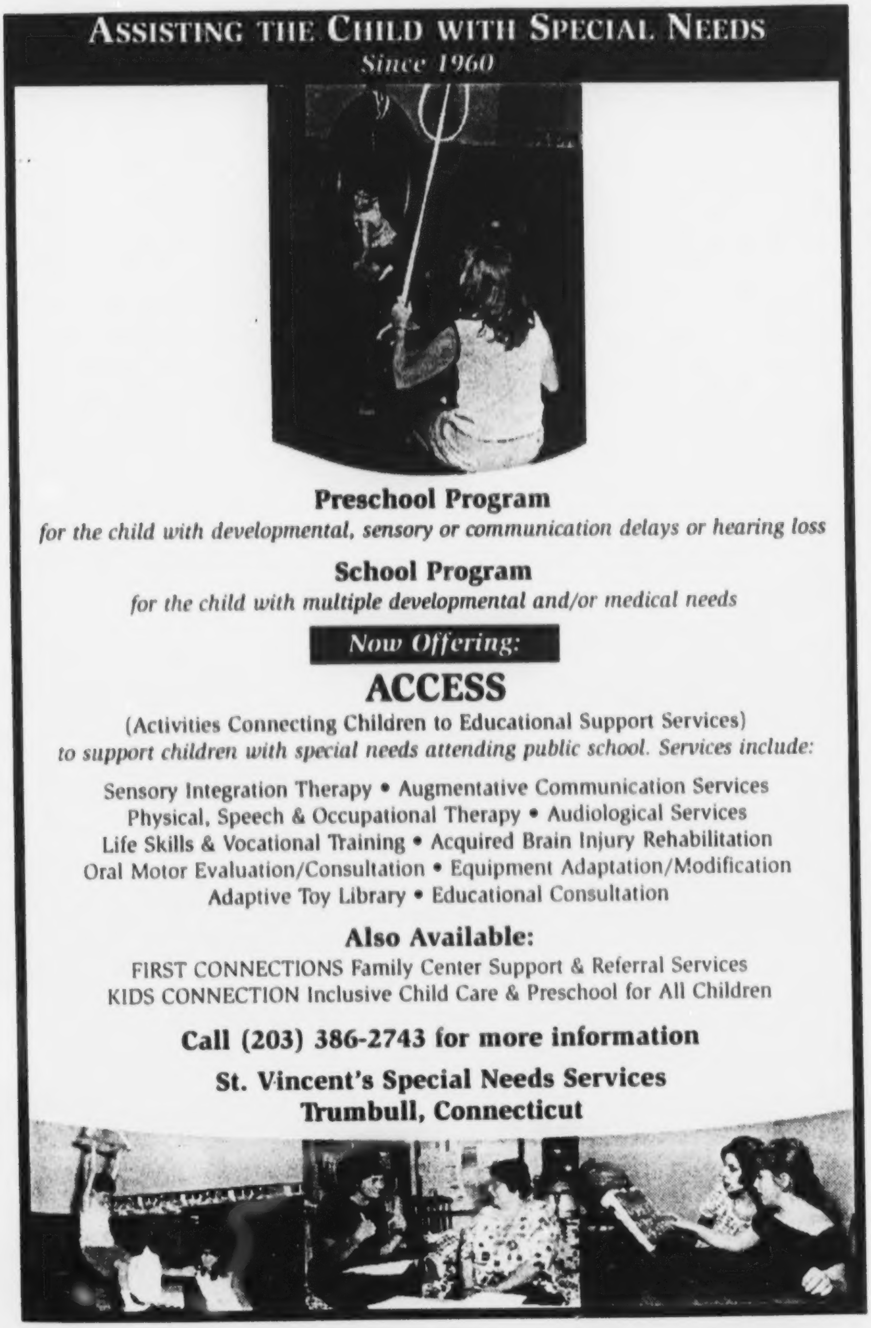
was and learned not to cross it. Gretchen needed her therapy, but she also needed her mom.

Had we ignored Gretchen's emotional needs and treated her as if she would never have all of the skills she has today, we would have created a self-fulfulling prophecy based on the doctors' predictions. That would have been horrific. But helping Gretchen gain the skills she has today, was in some respects the toughest part.



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For example, we wanted Gretchen to feel and taste what life was like outside of therapy and doctor visits. We would take Gretchen to the local park, fully attached to her monitors with other equipment in tow, and place her in the baby swing, sit with her on the slide, and hold her on the see-saw. We wanted to give her the physical and social experiences of all the other kids at the park. When we began bringing Gretchen to the park, she was 6 months old, yet she could barely hold her head up, let alone sit up by herself. She also couldn't swallow. This didn't stop us from wanting her to have the experience of tasting and eating food. So, when the ice cream truck would come by, we would always buy her a cup of ice cream. Even though she couldn't swallow, she could learn what ice cream tasted like. What hurt most during those times? The stares. Not so much from the other children, but from other adults. That was tough to take.

Looking back, it was all so new to my husband and me. We were faced with challenges that we never planned for or expected to face. We had to quickly learn how to take care of Gretchen and Rachel, and we had to learn how to get through the maze of medical, financial, legal, and educational issues that we continuously encountered. How did we do it? We got organized, got tough, and we immediately got down to business.

Shortly after Gretchen's birth, I contacted every government agency and non-profit I could find to request a packet of information. I also contacted local bar associations, special education departments, local children's hospitals and therapy centers and did the same. I became an expert at navigating the yellow pages and became friends with many librarians. With each packet I received I learned of one more resource I hadn't heard of before and contacted them. In a few short months, I had filled a four-drawer file cabinet with information about education laws, support groups, health insurance regulations, and therapy groups. You name it and I knew about it. I categorized the files by subject and created a section for my personal notes, mostly as they related to Gretchen. When I had the chance to speak to the school district about getting services for Gretchen when she was 2 years old, I was armed with the information I

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needed about her rights and local opportunities. Believe me, it makes all the difference in the world walking into that type of situation armed with up-to-date information.

In addition to finding all the right information, Doug and I had to battle through various systems, rules, and regulations to find the specialists, experts, and resources that could help our children. One battle in particular was when Gretchen started kindergarten in the public school system. We had completed the district's assessment process and it was time for the school to make the recommendations for her IEP (Individualized Education Plan). It was determined that Gretchen had the cognitive ability to be in a regular class but because of her physical limitations, they wanted her to attend school while seated in a wheelchair and wearing a helmet. She would also have to participate in adapted physical education classes.

The school district stated that their concern was for Gretchen's safety, but in my opinion, they were more concerned with being held liable if she got hurt from a fall while at school. By that time, Gretchen was fully ambulatory but walked slowly and wore orthotics up to the knees. She did fall on occasion and couldn't

Nadine Vogel, left, with SNAP advisor Layne Montesino at the first SNAP training program, held in 1998.

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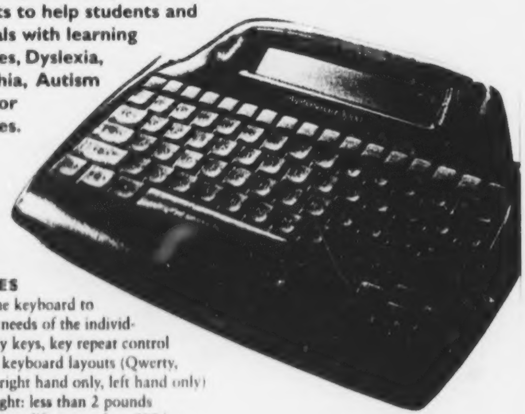

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independently get up, but she was walking on her own, and very proud of it. She worked extremely hard to get to that point.

I couldn't let this go without a fight. As a result, I brought in a team of experts, including physical and occupational therapists, a developmental pediatrician and an educational advocate. I also fought for Gretchen's rights under IDEA (Individuals with Disabilities Education Act), a major component of which states a child should always be placed in the Least Restricted Environment. Not only was the school's recommendation inappropriate by IDEA's standards, it would have greatly limited her socially, destroyed her emotionally, and removed any further motivation to improve her walking. At the conclusion of one meeting with the school district, I boldly stated, "You'll have to first put me in that helmet and wheelchair before you ever get to Gretchen." The result? We won. Gretchen was able to fully participate in regular physical education classes and attended school without the aid of a wheelchair or helmet. She did fall at times, and got her share of bruises, but she was never hurt. Instead, Gretchen was more motivated than ever to improve her gait and run like her peers.

Through our experiences, we realized very quickly that the biggest obstacle was finding the right people and programs to help our daughters. At the time Gretchen was born there was only one place that I knew of to go to for timely and accurate information. It was a local parent's support group for parents of young children with any type of special needs. We met twice per month and I would have moved heaven and earth to get to those meetings regularly. We found that other parents could provide a world of information based on their own recent experiences. If asked, most special needs parents would agree that they have learned more from other parents than from all the professionals combined. Sometimes newer parents don't feel emotionally ready for these groups, but from my personal experience, the information I received was worth every tear I shed.

Without more centralized places to go for information when Gretchen was born, it became a full-time job to decipher information, make phone calls, and get the help we needed. I often felt like the Mohammed Ali of special needs because each day I would put on my boxing gloves and ask, "Who am I going to have to fight today on behalf of my daughters?"

So, how do I do it? How do I stay in the ring? With every championship boxer, there's a championship coach, and that's my husband, Doug. Doug and I have known each other since we were 14 years old, and he is the most supportive husband any woman could wish for. I could never have accomplished the things in life

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that I have without him. Doug and I inspire each other, and our daughters inspire us. In addition, we have an incredibly supportive circle of friends. But I also have a tremendous amount of inner motivation to keep me going through those extra rounds.

My career

I wasn't born to be an advocate or a special needs expert. I didn't choose that career path right out of college. My life experiences made those decisions and choices for me and gave me the tools to share my knowledge and expertise with others. In many ways my professional and personal life have become intertwined and I have my children to thank for my accomplishments.

Challenges motivate me. I wasn't going to let "the system" get in the way of my children's care. Sure, it would have been easy not to think about the future, not to deal with the issues that my children would face as they got older. But when Gretchen was born and I saw how strong this little baby's will to survive was, my whole outlook on life changed. If she could fight, so could I. My weapons of choice? Education and knowledge. I decided to turn my own personal experiences into both a career and a mission to connect families with the resources and information they needed to help their own children with special needs.

From the moment I learned that Gretchen was born with a lifelong disability, I immediately began to think about her future. Who would be her advocate, friend, and supporter when I was gone? Who would take care of her financially? Who would provide for her in the future? These were daunting questions, even for someone like me. At the time Gretchen was born I had already been in the financial services industry for over four years and held an MBA in Financial Management. I knew all about the need for financial and estate planning, but when it came to my own family, and the specific issues facing families with special needs children, I was in the dark.

Over time, my husband and I worked out the financial and legal essentials of our estate plan. We met with our attorney and realized that there was still quite a lot to learn about special needs planning. It became very clear that getting the right information in a timely fashion is a major stumbling block for parents of special needs children. It is a challenge, and it motivated me to help bring answers to other families. The result? Special Needs Advocate for Parents (SNAP).

SNAP is a non-profit organization which I founded just 18 months after Gretchen was born. Its mission is to provide information, education, advocacy, and referrals to families of special needs children of all ages and abilities. The organization has proven to be extremely rewarding because through SNAP, families have a way of finding direction and achieving peace of mind when it comes to caring and planning for their most precious gifts: their children.

While each situation is different, the needs for proper estate and financial planning are very much the same. We all need to plan for our children's future. I knew I could help families face their fears of this type of planning, fears very often related to thinking about their children's future—a future without them.

> The organization has proven to be extremely rewarding because through SNAP, families have a way of finding direction and achieving peace of mind when it comes to caring and planning for their most precious gifts: their children.

In 1997, I saw an opportunity to bring my passion for advocacy into the workplace. MetLife offered me the opportunity to develop a program specifically designed to focus on the concerns of families with special needs children. MetLife has a strong commitment to both the special needs marketplace and work/family issues. In 1998, I launched MetDESK, MetLife's Division of Estate Planning For Special Kids.

MetDESK is one of the first programs of its kind in the financial services industry. What makes it especially unique is its network of dedicated specialists nationwide who provide customized financial solutions to meet families' needs. The majority of specialists are parents of special needs children or have a parent or sibling with special needs. Many are volunteers in the special needs community. In addition, each MetDESK specialist undergoes extensive training and continuing education to serve the distinctive issues facing families with special needs children. They understand first-hand what their clients are going through and they bring their expertise to the grassroots level. There are many financial issues parents of children with special needs have to think about, and with the help of a program like MetDESK, one of the greatest obstacles—finding the right information—can be removed.

My life

Douglas, Gretchen, Rachel, SNAP, MetDESK—my family, my advocacy, my career. My life. By mixing all these ingredients, I've created something very special, rewarding and fulfilling. The recipe for my life: balance—the way it should be. ■

Nadine Vogel is Assistant Vice President of Marketing at Metropolitan Life Insurance Company in New York City.

RESOURCES

For more information on SNAP, contact them at:
(888) 310-9889 or on their Web site: http://www.snapinfo.org.

For more information on MetDESK, contact them at:
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MEDICAL RESEARCH UPDATE

by David Chamalian

NEW TREATMENT FOR PRADER-WILLI SYNDROME APPROVED BY THE FDA

The FDA has recently issued its approval of a new form of growth hormone to treat growth failure in children with Prader-Willi syndrome (PWS). Although growth hormone therapy is not a new method for treating growth hormone deficiency, the new drug, Genotropin™, is the first to be approved specifically to treat PWS. The new treatment reportedly improves growth and body composition in children with PWS, stimulates skeletal growth, decreases body fat, and increases lean body mass. According to the Prader-Willi Syndrome Association USA (PWSAUSA), FDA approval may also make it easier to obtain insurance or Medicaid coverage for Genotropin. *Editor's note: As with any other drug, however, EP recommends consultation with a physician before beginning the treatment. For more current information on PWS, log on to the PWSA (USA) Web site at http://www.pwsausa.org; or see the July/August issue of The Endocrinologist for more information on this new treatment.*

COCHLEAR IMPLANTS: EARLY IMPLANTATION MAY IMPROVE SUCCESS

For five years researchers followed the progress of 40 children who are deaf who underwent cochlear implantation at an average age of 52 months. They assessed the children for "understanding of speech in conversation without lipreading" in an attempt to pinpoint indicators of speech perception. Studies done prior to implantation showed an average of zero words/minute perceived. Five years after implantation, however, the children were able to perceive words at an average rate of 44.8 words/minute. Children who received the implantation at an earlier age and those who used oral communication showed even more improvement over the others. While admitting that "the outcome of pediatric cochlear implantation is characterized by its variability," Gerard M. O'Donoghue, MD, and his colleagues from University Hospital in Nottingham, England, write, "The results clearly show that young congenital and prelingually deaf children can develop substantial speech-perception abilities up to five years after implantation." The study can be found in the August 5, 2 , issue of *Lancet*.

COPING-SKILLS THERAPY AND DIABETES MANAGEMENT IMPROVES METABOLIC CONTROL FOR ADOLESCENTS WITH DIABETES

Researchers from Yale University's School of Nursing have shown that training young people to cope with their disease concurrently with providing strict diabetes management instruction can prove both socially and clinically beneficial to them. In a recent study, which included a strict diabetes management regimen, Margaret Grey, MD, and her colleagues randomly assigned a portion of a group of 77 people, ages 12 to 20, to a behavior-intervention group, where they would also get training in social problem solving, cognitive behavior modification, and conflict resolution. The remaining portion, who were also assigned to the diabetes management regimen, were placed in a control group. At the completion of the training one year later, the intervention group showed lower glycosylated hemoglobin (when sugars in the bloodstream attach themselves to the hemoglobin) and achieved better diabetes and medical self-efficacy scores than the control group. Incidence of weight gain and hypoglycemia also decreased among the females in the intervention group (but not in males). Dr. Grey and her colleagues determined that among those in the intervention group in general, diabetes had less impact on their quality of life. Writes Dr. Grey of her group's findings, "The addition of behavioral intervention to intensive diabetes management in adolescence results in improved metabolic control and quality of life over one year."

RESEARCHERS CALL FOR MORE AGGRESSIVE TREATMENTS FOR SICKLE CELL DISEASE

The causes of acute respiratory attacks (also called acute chest syndrome) in people with sickle cell disease have recently undergone rigorous investigation due to the seriousness and sometimes fatal outcomes of such attacks. Led by Elliot P. Vichinsky, MD, and his colleagues at the Children's Hospital in Oakland, California, a recent study analyzed the DNA of lung fluid of 600 people who have sickle cell and experience respiratory attacks. Each of the people was treated more intensively than usual as well. The test results showed that in approximately 400 cases (about two-thirds), causes of the attacks could be attributed to one of two factors: bits of marrow from damaged bones getting into the lungs (also called pulmonary fat embolism), and infections from common pathogens that are not usually dangerous to most people. Researchers, therefore, recommend more aggressive, broader-range use of antibiotics to treat the infections. They also warn that the embolisms may be primary indicators of future respiratory problems. For more information on this study, see the June 22, 2000 issue of *The New England Journal of Medicine.*

Wanted: Wish List

Technology is just one tool in expanding EParent.com's resources, while the true value of the site is in delivering content that responds to its users, very specific and special needs.

These days, every other newspaper carries an article on the latest incarnation of everyday technological gadgets or tools that liven up the so-called Information Age: the Internet, the personal computer, the mobile phone, the handheld wireless device. Often, the focus of such articles is on the messenger (the tool) and not the message (the information). The fuss is understandable: How can we not stand in awe of the swiftness of advances in technology? On the other hand, we should not forget the more powerful element that gives meaning to such advances: the quality of information that is transmitted, and the communities that bring them to life.

EParent.com has introduced many new features thanks to our readers' involvement. Continue to e-mail us your suggestions at epedit@aol.com.

Providing useful, practical information has been EP's mission since its inception. While we are constantly finding ways to further improve the technologies behind our Web site, http://www.eparent.com, our main focus remains in the creation of quality content. In the 1970s, long before the Internet became a household word, EP was on to something that would eventually become a favorite buzzword among Web users decades later: "community." EP magazine pioneered and created a forum for its readers through the "Search & Respond" section to connect families whose children had similar disabilities so that support and knowledge could be shared among them. Search & Respond has always been one of EP magazine's more popular sections and continues to thrive and grow with an online version that accommodates a faster exchange of messages.

For the past three years since EP built EParent.com, we have extended a request to every member of our audience to contribute ideas and participate in online discussions. This simply reflects EP's philosophy that parents themselves are the best sources of ideas, as they are totally immersed in raising the child or young adult with a disability. The response to our request has always been very encouraging, and our Web site has grown considerably in terms of resources. Our continuing goal is to enable parents and professionals to communicate messages by harnessing the Web's interactivity, access EP's award-winning editorial, information from our customized medical reports, the EP Library, and updated content from our November 10-12 conference, the World Congress & Exposition on Disabilities.

What's new?

Many of you might have, in fact, noted the features that EP has introduced on the Web during the past year, thanks to your ideas and suggestions:

- Fully-expanded "Search & Respond" channel with many more disability categories. We encourage all of you to visit this section and continue to share your experiences and information with families who are new to the site and disability community.
- More directories (under the "Resources" channel) such as those for Schools, Camps & Residences; Van and Van Conversion Dealers; and Products & Services.
- Monthly "Survey" section posting questions relating to articles in development for future issues of EP magazine, such as your ideas for Halloween costumes.

EParent.com is "Bobby-Approved," which means it meets Center for Applied Special Technology's (CAST [Web site: http://www.cast.org]) standards for online accessibility.

The good news is that EP has reached the point of carrying out plans to build an even deeper fountain of resources around those that already exist, as well as to upgrade our Web site's technology. Once again, we remind you that the EP Web site is yours, and ask that you e-mail us at **epedit@aol.com** with your "wish list" for Internet features, ideas, and recommendations for improvement. Remember, communications technology is only as good as the information it transmits. ■

E-mail your comments on this article, or other ideas or suggestions for EParent.com, to:
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Director of Internet Business Development and Sales, at:
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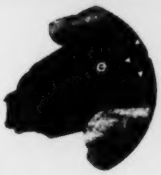

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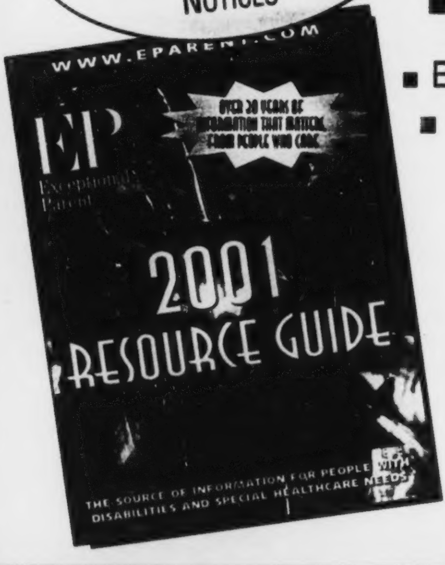
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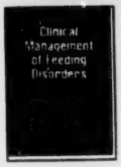

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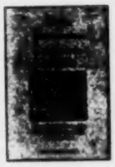

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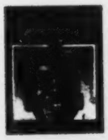

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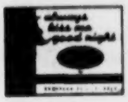

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ASPER[illegible] SYNDROME

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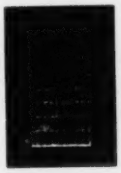

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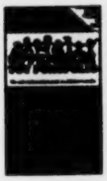

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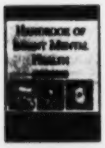

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Sandra Z. Kaufman **NEW!**
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INCONTINENCE

Toilet Talk

by Ginny Paleg, PT, Amy McHugh, OT, and Camille Jackson, OT

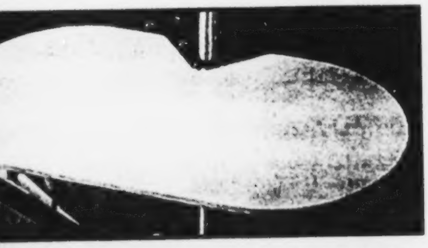
You read last month's article in EP on potty training and were totally motivated to start the process. Then you realized you had no equipment, were not sure how to transfer or position your child, and didn't know what to do about inaccessible clothes. Well, here we are to help you out! We spoke with many parents, scoped out different trade shows, and researched options and strategies to make potty training and toileting a little bit easier. We hope you find some helpful tips in the following article.

Transfers

Transferring from wheelchair seat to toilet takes time, so plan ahead! If you wait until it is urgent, you cannot take the time needed to perform the safest, most independent transfer possible. Use a schedule to decrease the urgency of the transfer so you feel successful and continue toward independence. The ultimate goal is for the child to be as independent as possible.

At home, there is lots of space as well as privacy and you know it is clean. You will need a whole different strategy in a tight, cramped stall. Parents can use several types of transfers at home depending on the size and age of the child. Here are some descriptions of transfers to help you pick out which one will work best for you and your child.

- During a dependent transfer or total lift, the adult does all the work to transfer the child from the wheelchair to the toilet. We found this works best when the child is undressed before transferring. The child is totally dependent on the parent to move him or her from one place to the other and back. This transfer may require more than one person depending on the size of the child. It is always important to remember proper body mechanics so no one is injured.
- use your legs, not your back or arms
- spread your legs to shoulder width
- do not twist
- keep child as close to your body as possible
- A stand-pivot transfer requires the child to stand from sitting and take small steps or pivot his or her body toward the commode for sitting. This transfer can require different levels of assistance by the parent to make it successful. To perform this transfer, the child must first be positioned at the edge of the wheelchair with feet placed firmly on the floor. The parent will position his or her own body directly in front of the child with knees bent and touching the child's knees for support when standing. The parent will position his or her arms around the child's waist and hold the back of the pants. The child can be positioned as if he or she is giving the parent a big hug or can hold onto the arms of the chair to offer as much assistance as possible. The parent will count to three and rock back and forth with the child. On three, the parent and child will stand while the parent lifts up and pulls the child forward. It is important for the parent to remember to use his or her legs while standing. Together, parent and child will take several small steps or pivot toward the toilet. While standing in front of the commode, remove clothes. If the child can reach back to a supporting surface, have him or her do so to help lower into a sitting position.



A transfer board can be used with a child who has poor leg strength but good upper body control. Available from Abilitations (800) 850-8603.

The stand-pivot transfer is a complicated maneuver that must be performed with plenty of time allotted to get to the toilet.

- The squat-pivot is similar to the stand- pivot transfer. This transfer does not require the child to completely stand to transfer. Follow the same steps as the stand-pivot transfer using squatting to move the child from one place to another. Since this transfer may seem more awkward, the parent may want to remove clothes upon initial squatting.
- Transfer boards are flat boards.

continued on page 98

Charles C Thomas
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Circle #30

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The child is placed with one edge of the board on the wheelchair and the other on the toilet seat. Using a transfer board requires practice. Initially the parent may have to position the transfer board for the child. This transfer is ideal for the child with good upper-extremity and trunk control but poor leg strength/control. Positioning dycem (a non-skid material) onto the seat of the commode prevents the board from slipping.

The child can scoot himself or herself onto the commode using his or her arms to push toward the commode. This child may want to remove his or her clothing before transferring by leaning side to side in the chair. Another option when using a transfer board is to cover it with a pillowcase. This will help the child slide towards the toilet when clothing has been removed.

"We placed Shawn's toy walker around a child-sized toilet to provide the support he needs when he uses the toilet"— Marian Ethridge, Shawn's Gramma.

Positioning

Positioning your child is very important during toileting. The child needs to be in a relaxed environment to perform the required functions. Depending on your child's postural control, there are many positions that can be used to facilitate normal toileting. If your child has high tone, toileting will be more successful when his or her tone is reduced prior to initiating toileting. Here are some positions that can help. The child should have his or her feet supported using the ground, step stool, or leg rests from a positioning device to allow his or her energy to be devoted to urinatin or moving the bowels instead of postural control. Maximal hip flexion and forward leaning may also be helpful. Asking your child to exhale slowly helps relax the muscles needed to void. Other people are more successful leaning backward a few degrees. Commodes can be purchased that have adjustable legs; seat belts; safety bars; angled legs for stability; and padded, upholstered, adjustable backrests and headrests to supply the appropriate support to accommodate the child's needs. There are units that can be purchased that will roll over a standard toilet and which accommodate your child's positioning needs.

This way of positioning on the toilet is an alternative for boys who cannot stand.

A caregiver supports a child who is in the traditional, outward-facing toileting position.

Supporting the shoulders can help provide stability for a boy who is standing to urinate.

A child with low tone can be placed in a positioning device that will provide him or her with the support he or she needs to be successful in toileting. A caregiver's hands and body can provide the postural control to a child with low tone need. There are specific recommendations for positioning children with other disabilities. An occupational or physical therapist can help you determine which is the best option for your child. We have included some photos and descriptions of models to get you started.

Adding a table in front of your child to provide support when he or she needs it also assists with forward leaning. There are several other positioning options available. A boy can be given support to the shoulders or pelvis as seen in the picture below or by leaning on grab bars while standing to urinate.

The child is given support while seated facing the back of the toilet. The front approach, or frontal mount, is a great position for a child who cannot stand to transfer or who needs to be transferred quickly. This also directs the flow of urine away from the caregiver, especially when working with boys.

The child can be positioned in the traditional toileting posture facing out. The child can be given support from behind with the caregiver straddling the toilet or from the front with support provided by the caregiver where the child needs it most.

The key to successful positioning is that the experience should be as normal as possible and the same sex caregiver (if available) can be a role model to normalize the

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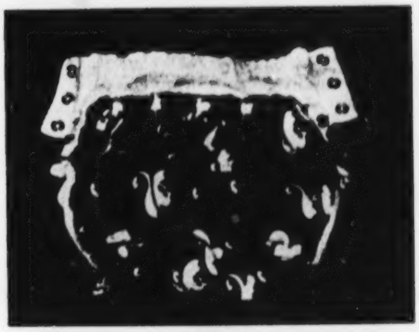
experience. It is important to individualize the training and help the child become as independent as possible.

Bathroom adaptations

Most home bathrooms are not accessible and require modification for a child who uses a wheelchair or walker. Grab bars should be installed for safety and support. The toilet seat height can be adjusted by adding a raised toilet seat, or a device installed under the toilet to add height to the toilet for easier transfers. A child-size toilet can be purchased for a lower cost until the child is large enough to fit onto a regular- sized toilet. Below, are various supportive toileting devices. The bedside commode can be positioned next to the child's bed for independence in nighttime toileting. This will reduce the traveling back and forth to the bathroom, reducing the risk of falls.



A diaper with snaps helps with quick removal for toileting.

Adapted clothing

Clothing can be adapted to accommodate the needs of exceptional children. Velcro brand fasteners can be substituted for buttons, zippers, and snaps to allow easier and quicker removal and fastening of clothing during toileting. Wrist or finger loops can be added on pants or shorts to allow easier donning after toileting or while getting dressed for children with difficulty with fine motor control. One mother we spoke to, Teresa Kendrick, offered this advice: "[My daughter] Amanda sustained a traumatic brain injury when she was 2. Amanda was non-verbal, non-ambulatory, ate through a G-tube and breathed through a trach. It took us a few years, but now she signs 'potty' when she needs to go, gets herself to the bathroom, pulls up on the potty, and even gets her pants off by herself. The key to this was a Velcro fastened diaper that she could pull off with her good hand. This diaper also had a pad in case of accidents."

Snap crotches can be added to pants for quick and easy removal during toileting or diaper changes. Absorbent lining can be added to the area of pants

continued on page 100

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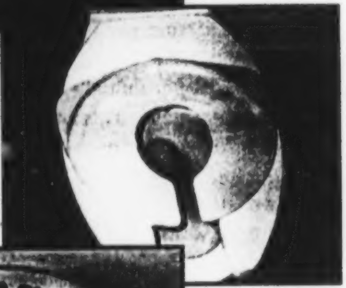

Toilet seat minimizers (above and right) help children feel safe while sitting on a full-size toilet.

INFLATE-A-POTTY

An inflatable potty is a portable, easy to use potty. It makes "emergencies" less of a problem. By Brite Time, Inc. (866) 676-1646.

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between the legs to absorb additional wetness between diaper changes.

An easy solution is to buy clothing one size too big with elastic waistbands such as sweat pants or jogging pants. Many nylon sweat pants have zippers or snaps that extend from the ankle to the waist for easy removal during toileting or diaper changes. It is important to remember that there are options for adaptive clothing available commercially through catalogs and through many others online. Adapting clothing can allow your child to be more independent and help you make toileting more successful.

Toilet adaptations

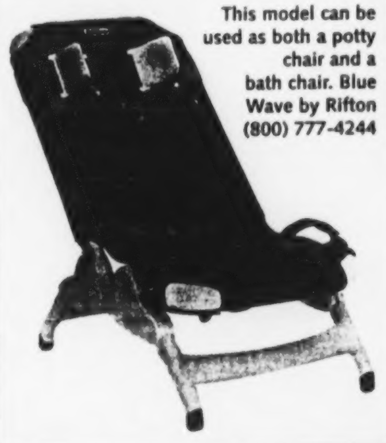
A toilet seat minimizer is essential for small children who may slip into the water. These soft models make the child feel secure.

A folding potty seat is wide enough to cover all toilet seats and conveniently folds in quarters to fit easily into a diaper bag or glove compartment.

Potty chairs

For kids with cortical blindness and other visual impairments we found musical potties might work. Special sensors in the potty are triggered when moisture is present, playing cheerful tunes. The feedback is conditional, positive, immediate, and consistent. Another variation are potties that make "flushing" noises.

There is an inflatable potty called "Inflate a Potty" that fits inside a pocket-size carrying pouch. Inflate the potty quickly by blowing it up like a beach ball, using a removable extension tube. Insert a disposable garbage bag and cover the potty completely. After use, remove and seal the bag and dispose of it.



This model can be used as both a potty chair and a bath chair. Blue Wave by Rifton (800) 777-4244

Tongs can be used to help a child grab the toilet paper for wiping.

"Emily is 4, has spastic diplegia and crawls everywhere. She occasionally uses a walker and we use it in front of her to support her body on a regular toilet seat."
—Emily's mom, Diana Sinton

We also found a "potty context." This little cardboard bathroom scenery prop can be used as a privacy screen, when the real bathroom is not available, or when you want to discuss bathroom words and need a visual context.

Splashguards can be useful for boys who are sitting to urinate. Care must be exercised when getting on or off the potty, however. By Columbia Medical (800) 454-6612.

Supportive devices

Not all equipment is "created equal." We found differences in weight, portability, ease of storage, and ease of cleaning. Models that offer varying amounts of support can grow as your child improves his or her motor skills, especially trunk control.

There are a few models that can be easily removed so others can use the facilities. Some

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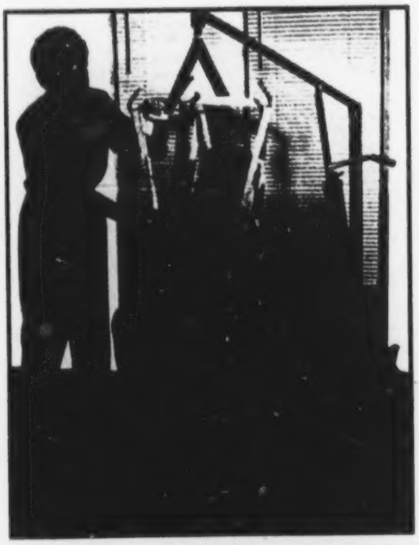

This system can be used for transportation to the bathroom, lifting, and assistance in walking. By Barrier-Free Lifts (800) 582-8732

potty-chairs can be used as bath chairs and floor sitters as well. For boys, a splashguard can be useful. *(Please note: care must be exercised when child is getting on or off the potty to avoid injury.)* Adjustable footrests are also a must. Kids have to feel secure and stable in order to relax their "elimination" muscles. Most folks find 45 degrees of hip flexion is the best for getting quick elimination.

Here are two multi-use bath systems we found that offer tilt and recline as well as a height adjustable frame. The seat can be removed and used as a toilet seat or bath seat. The footrest is also angle adjustable, which really helps in getting good hip flexion with feet flat on the footboard. The wheels on the base can be locked securely. Both systems fold flat for storage and transport.

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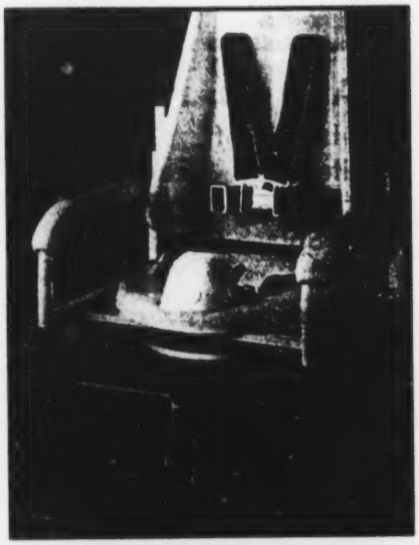

Bedside commodes can be useful at night, when a trip to the bathroom is not practical. By Columbia Medical (800) 454-6612.

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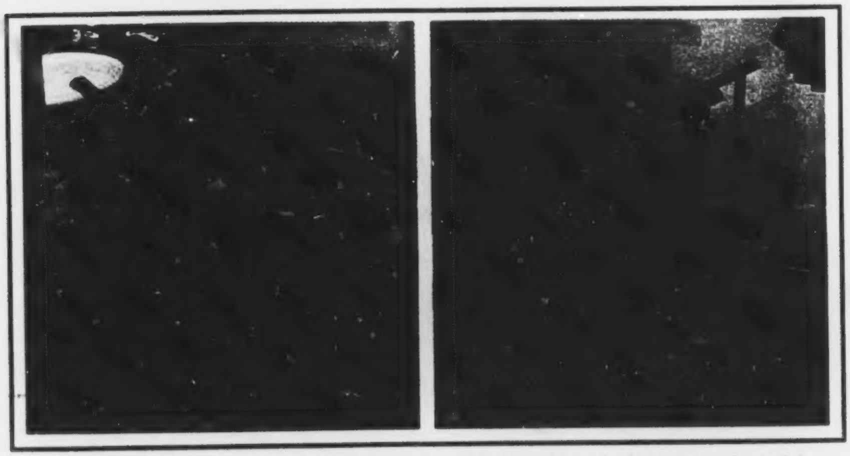

This item was custom built, and can be used as a footrest for a child sitting on the toilet, and, when turned around, as a step stool for using the sink. Emily Sinton uses this to help with her daily toileting.

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There are also toilet seats that secure to the toilet. A favorite feature is a pummel, a block or wedge between the legs that stop the knees from hitting together and the child from slipping forward. This helps kids who are always scooting their bottoms forward and slipping out of the seat.

We found another system that runs on tracks mounted on the ceiling. The tracks can run from the bedroom to the bathroom and more. The harness can be used for lifting and even assisted walking.

Bedside commodes

There are some bedside commodes that are self-cleaning. Snap off the top part, fit it on top of the toilet, and flush. The water from the toilet swirls and cleans the contents of the commode tray.

Bidets

We found a bidet that fits over your regular toilet and has an automatic sensor to turn on and off. This is great for kids who cannot wipe. A bidet cleanses naturally with a soft, soothing, aerated stream of warm water. It is conveniently activated by an easy-to-use remote control that extends the bidet wand at the touch of a button and retracts completely when finished. Additionally, an innovative automatic air deodorizer quickly eliminates all toilet odors. There is even an optional, comfortable, warm-seat feature. You can install this bidet on an existing toilet by simply replacing the standard seat.

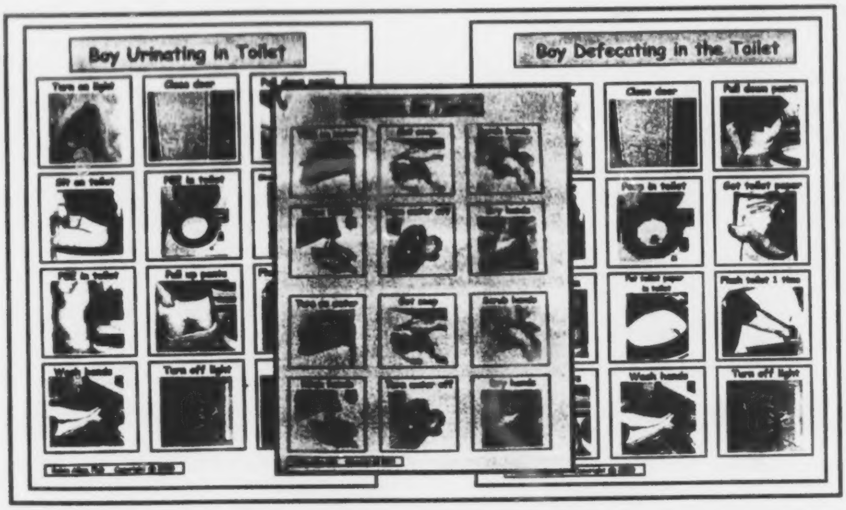
Other equipment

There are helpful items on the market that will help children perform self-care after toileting. These toilet aides allow the child who cannot quite hold on to the toilet paper or reach around to their bottom to wipe efficiently. The first toilet aid has a curved, extended handle and recessions that grip the toilet paper. Kitchen tongs used solely for bathrooms also serve the same purpose for helping the child to wipe himself.

Summary

Potty training can be a long complicated road. You may find yourself taking the first exit, learning the best lying down diaper change. We hope your travels take you further after reading this article and you try the standing diaper changes. And for those in for the long haul, do not give up until you reach the last exit, and come to the land of the royal flush, a fully potty-trained child! We wish you success and lots of dry diapers. Please contact us if you have specific questions or have other helpful ideas we can pass on. ■

Ginny Paleg, PT, Amy McHugh, OT, and Camille Jackson, OT, are pediatric therapists at the Hospital for Sick Children in Washington, DC. They can be reached at (800)226-4444. Ginny can be reached by email at gpaleg@hospsc.org


Boy Urinating in Toilet
Turn on light
Close door
Pull down pants
Sit on toilet
Pee in toilet
Pee in toilet
Pull up pants
Wash hands
Turn off light
Get soap
Scrub hands
Turn on water
Turn water off
Dry hands
Boy Defecating in the Toilet
Close door
Pull down pants
Poop in toilet
Get toilet paper
Put toilet paper in toilet
Flush toilet 1 time
Wash hands
Turn off light

"Tony has autism. He could use a regular potty-chair, but we needed a way to communicate with him about the whole process. We used a pre-made task analysis board (above). The board can be hung in the area where Tony will follow the visual steps. Tony points or touches the visual step and then does it"—Tony's mom.

"Potty Boards" available from Step Seminars, Inc. (301) 495-8824

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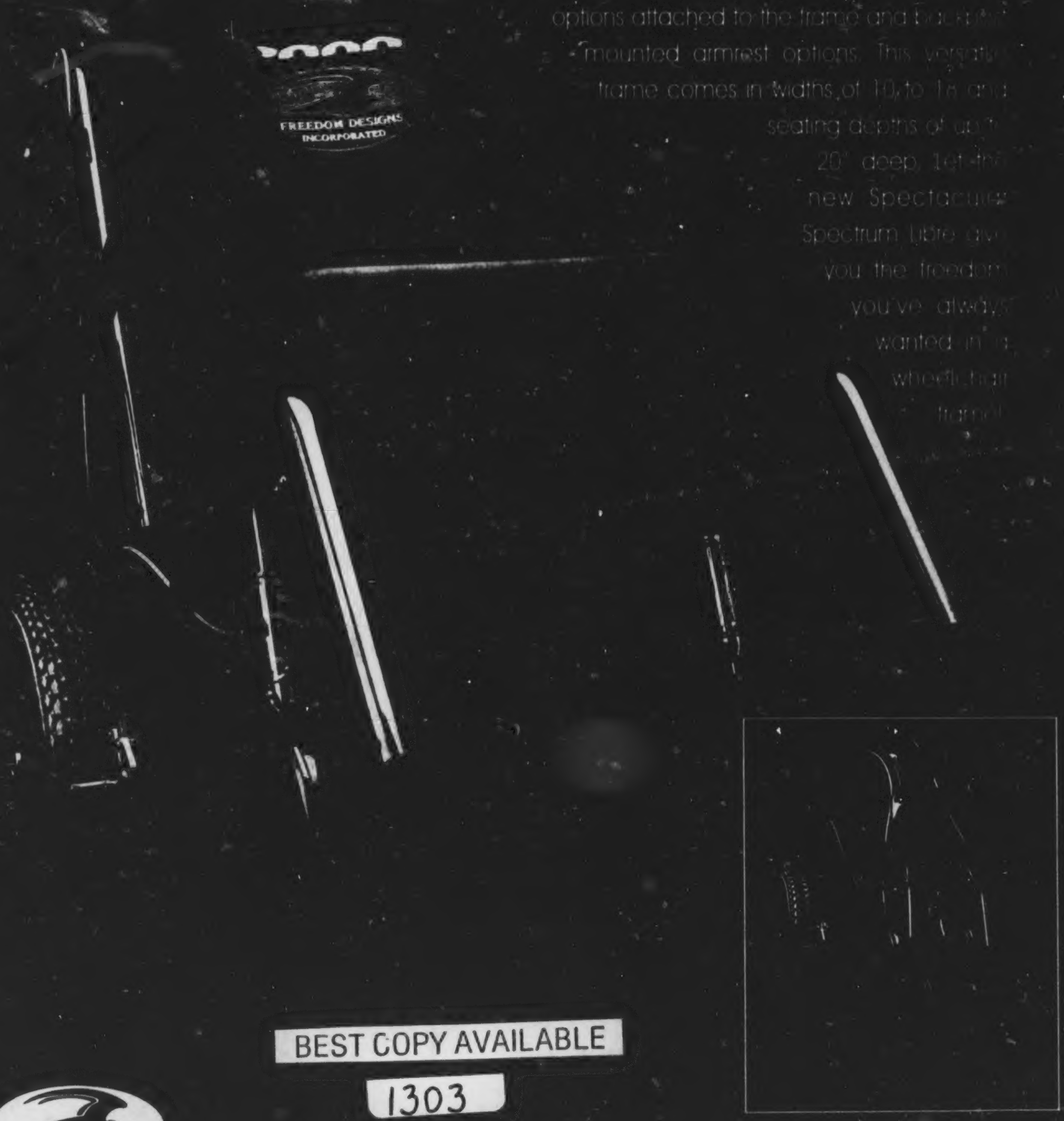

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Circle #4[illegible]

Parents As Partners In The Medical Home

Parents Monitor Their Child's Health Status

by Tanis Bryan, PhD
and Karen Burstein, PhD

Contributors:
David Hirsch, MD, FAAP
Diana Frieberg, BSN,
Mae Moore,
Phoenix Pediatrics
Judie Walker,
Raising Special Kids

Although professionals and parents endorse family-centered care, significant barriers remain. Parents frequently exclaim about healthcare professionals, "If they would just listen!" while professionals complain that parents lack the communication skills necessary to give adequate information. These are the findings of our research team of parents and professionals on the Parents as Partners in the Medical Home Project. As reported in previous issues (*EP, Aug-Oct. 2000*), the Medical Home is a concept of how pediatricians should provide the types and extent of services needed by children with special healthcare needs and their families. Family-centered care is a significant component of the Medical Home. The two principles that define family-centered care are: 1) parents are the child's primary source of support and they are experts on their own children; and 2) families and professionals working together best shape practices and improve healthcare. Given the extensive role of families in caring for children with special healthcare needs, it is clear that parents need communication skills and strategies for ensuring that healthcare providers actively listen to their information and concerns.

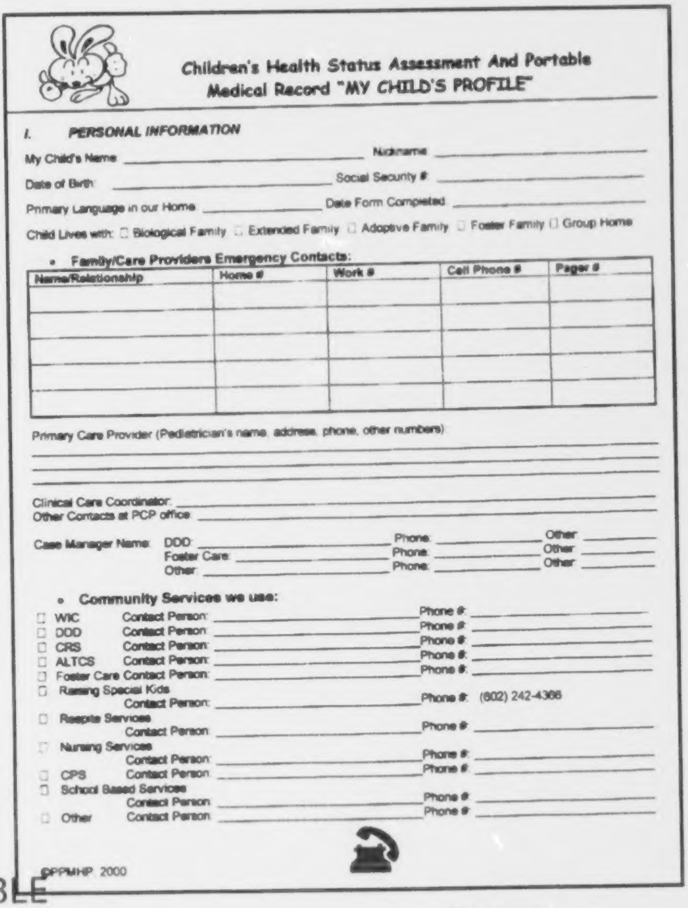
Parents on the front line of child assessment and communication

In order to help correct this deficit, our researchers created the Children's Health Status Assessment (CHSA), a portable, comprehensive medical record that allows parents to track their child's health problems, communicate information to providers, and evaluate the effects of treatments. In coming up with the CHSA, our researchers started with the belief that the parents' role as partner on the medical team requires them to be effective communicators, which in turn should make them more credible to professionals. The best way to do this was to increase parents' communication effectiveness by having them systematically track their child's health status in a form that could be easily presented to providers. An added benefit of this health assessment, the team anticipated, would be that the child's health would improve because systematic tracking would allow parents to:

(1) detect and monitor problems early in their onset;
(2) track the events leading to changes in their children's health status; and
(3) evaluate their child's responses to medical interventions.

The team determined that a useful record had to help parents:

- become knowledgeable about their child's health status and efficiently communicate changes, and become familiar with relevant medical terminology (to make them comfortable when care providers use medical language, and to feel confident asking questions);
- identify and communicate problems early;



Children's Health Status Assessment And Portable Medical Record "MY CHILD'S PROFILE"

I. PERSONAL INFORMATION

My Child's Name ______________ Nickname ______________
Date of Birth ______________ Social Security # ______________
Primary Language in our Home ______________ Date Form Completed ______________
Child Lives with: ☐ Biological Family ☐ Extended Family ☐ Adoptive Family ☐ Foster Family ☐ Group Home

- **Family/Care Providers Emergency Contacts:**

Name/Relationship	Home #	Work #	Cell Phone #	Pager #

Primary Care Provider (Pediatrician's name, address, phone, other numbers)
____
____
____

Clinical Care Coordinator: ______________
Other Contacts at PCP office ______________

Case Manager Name: DDD: ______________ Phone: ______________ Other ______________
Foster Care: ______________ Phone: ______________ Other ______________
Other: ______________ Phone: ______________ Other ______________

- **Community Services we use:**

☐ WIC Contact Person: ______________ Phone #: ______________
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☐ CRS Contact Person: ______________ Phone #: ______________
☐ ALTCS Contact Person: ______________ Phone #: ______________
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☐ School Based Services Contact Person: ______________ Phone #: ______________
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Left: The Child Profile section of the Children's Health Status Assessment and Portable Medical Record.

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- easily maintain an ongoing record of illnesses, interventions, and the outcomes of treatment, organizing the child's records in a way that makes them easily accessible to all who have need of the information and useful for planning and decision making; and
- track out-of-pocket expenses—for purposes of taxes, budgeting, qualifying for insurance coverage, or services.

The team organized the CHSA into three sections, making it user-friendly, flexible, and allowing parents to individualize it for their family's needs. The sections are: 1) Child Profile and Medical Information, and Supply, Expense, and Communication Logs, 2) Gated Daily Assessment/Weekly Planner Calendars, and 3) Appendices.

Child Profile and Medical Information; and Supply, Expense, and Communication Logs

Children with special healthcare needs often have complex, long-lasting medical problems that require attention from many specialists in addition to their primary care pediatricians. Each provider may focus on a different problem that entails a specific treatment, and each produces medical records. Although specialists may send copies of reports to primary care pediatricians, parents are the natural link between providers, and the only party with first-hand knowledge of all the procedures and outcomes. The parent has to communicate information about the child's status to each of the providers, ensure that each is aware of the others' prescriptions, and make information accessible to all who work with the child.

The CHSA provides one place where all the information is organized and available for immediate access. **The Child Profile and Medical Information** section contains forms to organize all the information. The first step is to simply gather all of the child's medical records, reports, and documents. The next step is to put them in chronological order, and then enter the information onto the following forms:

A) **Emergency Information Form for Children with Special Needs.** The American College of Emergency Room Physicians and the American Academy of Pediatrics developed the Emergency Information Form. The Form includes the child's:

- Current and past health status, including base line vital signs;
- Immunizations;
- List of healthcare providers;
- Medications, foods, and procedures to be avoided; and
- Common presenting problems/findings with specific suggested managements.

We suggest adding information about pri-

continued on page 106

Tim and his daughter Carrie.......
a young adult with Down Syndrome

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Tim and Carrie Bergeron

Tim Carrie !!

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Circle #26

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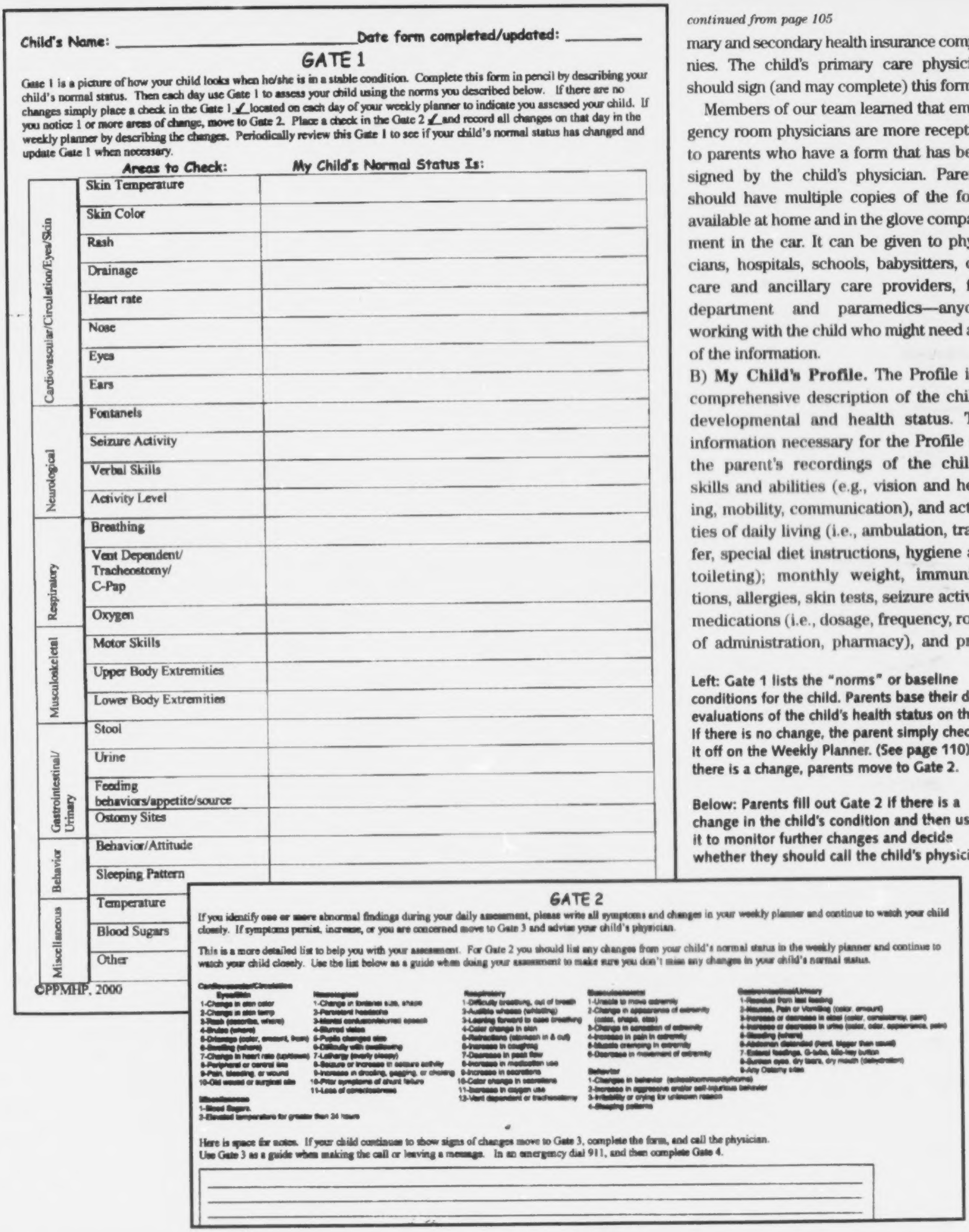
continued from page 105

mary and secondary health insurance companies. The child's primary care physician should sign (and may complete) this form.

Members of our team learned that emergency room physicians are more receptive to parents who have a form that has been signed by the child's physician. Parents should have multiple copies of the form available at home and in the glove compartment in the car. It can be given to physicians, hospitals, schools, babysitters, day care and ancillary care providers, fire department and paramedics—anyone working with the child who might need any of the information.

B) **My Child's Profile.** The Profile is a comprehensive description of the child's developmental and health status. The information necessary for the Profile are the parent's recordings of the child's: skills and abilities (e.g., vision and hearing, mobility, communication), and activities of daily living (i.e., ambulation, transfer, special diet instructions, hygiene and toileting); monthly weight, immunizations, allergies, skin tests, seizure activity, medications (i.e., dosage, frequency, route of administration, pharmacy), and prob-



Child's Name: ______________________ **Date form completed/updated:** __________

GATE 1

Gate 1 is a picture of how your child looks when he/she is in a stable condition. Complete this form in pencil by describing your child's normal status. Then each day use Gate 1 to assess your child using the norms you described below. If there are no changes simply place a check in the Gate 1 ✓ located on each day of your weekly planner to indicate you assessed your child. If you notice 1 or more areas of change, move to Gate 2. Place a check in the Gate 2 ✓ and record all changes on that day in the weekly planner by describing the changes. Periodically review this Gate 1 to see if your child's normal status has changed and update Gate 1 when necessary.

	Areas to Check:	My Child's Normal Status Is:
Cardiovascular/Circulation/Eyes/Skin	Skin Temperature	
	Skin Color	
	Rash	
	Drainage	
	Heart rate	
	Nose	
	Eyes	
	Ears	
Neurological	Fontanels	
	Seizure Activity	
	Verbal Skills	
	Activity Level	
Respiratory	Breathing	
	Vent Dependent/ Tracheostomy/ C-Pap	
	Oxygen	
Musculoskeletal	Motor Skills	
	Upper Body Extremities	
	Lower Body Extremities	
Gastrointestinal/ Urinary	Stool	
	Urine	
	Feeding behaviors/appetite/source	
	Ostomy Sites	
Behavior	Behavior/Attitude	
	Sleeping Pattern	
Miscellaneous	Temperature	
	Blood Sugars	
	Other	

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GATE 2

If you identify one or more abnormal findings during your daily assessment, please write all symptoms and changes in your weekly planner and continue to watch your child closely. If symptoms persist, increase, or you are concerned move to Gate 3 and advise your child's physician.

This is a more detailed list to help you with your assessment. For Gate 2 you should list any changes from your child's normal status in the weekly planner and continue to watch your child closely. Use the list below as a guide when doing your assessment to make sure you don't miss any changes in your child's normal status.

Cardiovascular/Circulation Eyes/Skin
1-Change in skin color
2-Change in skin temp
3-Rash (describe, where)
4-Bruise (where)
5-Drainage (color, amount, from)
6-Swelling (where)
7-Change in heart rate (up/down)
8-Peripheral or central line
9-Pain, bleeding, or wound
10-Old wound or surgical site

Miscellaneous
1-Blood Sugars
2-Elevated temperature for greater than 24 hours

Neurological
1-Change in fontanel size, shape
2-Persistent headache
3-Mental confusion/slurred speech
4-Blurred vision
5-Pupils changes size
6-Difficulty with swallowing
7-Lethargy (overly sleepy)
8-Seizure or increase in seizure activity
9-Increase in drooling, gagging, or choking
10-Prior symptoms of shunt failure
11-Loss of consciousness

Respiratory
1-Difficulty breathing, out of breath
2-Audible wheeze (whistling)
3-Leaning forward to ease breathing
4-Color change in skin
5-Retractions (stomach in & out)
6-Increase in coughing
7-Decrease in peak flow
8-Increase in medication use
9-Increase in secretions
10-Color change in secretions
11-Increase in oxygen use
12-Vent dependent or tracheostomy

Musculoskeletal
1-Unable to move extremity
2-Change in appearance of extremity (color, shape, size)
3-Change in sensation of extremity
4-Increase in pain in extremity
5-Muscle cramping in extremity
6-Decrease in movement of extremity

Behavior
1-Changes in behavior [illegible]
2-Increase in aggressive and/or self-injurious behavior
3-Irritability or crying for unknown reason
4-Sleeping patterns

Gastrointestinal/Urinary
1-Residual from last feeding
2-Nausea, Pain or Vomiting (color, amount)
3-Increase or decrease in stool (color, consistency, pain)
4-Increase or decrease in urine (color, odor, appearance, pain)
5-Bleeding (where)
6-Abdomen distended (hard, bigger than usual)
7-Enteral feedings, G-tube, Mic-key button
8-Sunken eyes, dry tears, dry mouth (dehydration)
9-Any Ostomy sites

Here is space for notes. If your child continues to show signs of changes move to Gate 3, complete the form, and call the physician.
Use Gate 3 as a guide when making the call or leaving a message. In an emergency dial 911, and then complete Gate 4.

Left: Gate 1 lists the "norms" or baseline conditions for the child. Parents base their daily evaluations of the child's health status on this. If there is no change, the parent simply checks it off on the Weekly Planner. (See page 110) If there is a change, parents move to Gate 2.

Below: Parents fill out Gate 2 if there is a change in the child's condition and then uses it to monitor further changes and decide whether they should call the child's physician.

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lems or treatments (i.e., illness, injury, procedures, hospitalizations).

Information related to family history as well as issues of guardianship (e.g., Medical Power of Attorney) can be included here.

The Profile is also the ideal place to include: the names, addresses, and telephone numbers of family members and care providers to contact in case of emergency; insurance information; information about the child's school (e.g., teacher, nurse, IEP date, transportation); community-based services and therapies; equipment and supplies; and medical specialists.

Finally, the Profile also contains the child's usual baseline status. Parents first have to establish what is "normal" for their child (e.g., skin temperature and color, eating habits). In other words, if the child typically has warm, moist skin, that is the normal condition of that child, rather than a signal that the child may need medical attention.

The completed Profile provides a precise summary of relevant information about the child that can be shared with physicians, schools, hospitals, or anyone that provides services to the child. It is a "snapshot" of the child's overall status at the present moment and should be regularly reviewed and updated.

Supply, Expense, and Communication Logs are where parents can keep track of equipment, disposable items, and any out-of-pocket expenses resulting from meeting the child's needs. The Logs are helpful for reordering items, recording conversations with healthcare providers, insurance authorization, transition from one insurance company to another, and tax information. Examples of out-of-pocket expenses include, but are not limited to, disposable items not paid for by insurance (e.g., diapers, over the counter medications), and mileage to and from medical appointments.

Gated Assessment/ Daily Planner Calendars

All parents check their children many times each day. Parents look at their children in the morning when they wake, feel their skin, assess the child's response when asking what the child wants for breakfast or about what happened at school. The CHSA uses three levels of assessment, or gates in which the parent: (1) screens the child from head to toe each day; (2) rates the child's physical, cognitive, and behavioral status; and (3) describes in detail the events that preceded and followed changes in the child's status.

Gate 1: Parents assess and record their child's health status on a daily basis. The purpose is to detect any changes in the child's "normal" status early, to monitor the changes in a systematic fashion, and to communicate changes to the appropriate

continued on page 109

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Circle #43

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SMART CARD

Child's Name: ____________ Child's Nick Name: ____________

Parent's/Caregiver's Name: ____________

Address: ____________ City: ________ State: ______ Zip: ______

Phone: (   ) ________ Cell: (   ) ________ Work: (   ) ________ Pager: (   ) ________

Parent's/Caregiver's Name: ____________

Phone: (   ) ________ Cell: (   ) ________ Work: (   ) ________ Pager: (   ) ________

Primary Care Physician's Name: ____________ Phone: (   ) ________ Fax: (   ) ________

Emergency Contact's Name: ____________ Relationship: ______ Phone: (   ) ________

Primary Diagnosis: ____________

Secondary Diagnosis: ____________

Know Reinforcers (things that your child likes that will help comfort him/her, activities he/she enjoys, or any dislikes): ____________

Feeding Instructions: ____________

Known Allergies (list any allergies and your child's reaction): ____________

Insurance Information:

Name of Insured	Insurance Company	Address	Policy & Group Number	Phone

Current Medications and Treatments:

Name of Medication	Dose	Time Meds Due	Route (how to give)

Clip and Save: Parents or the child's physician can fill out the Smart Card (above) and give copies to anyone who needs to have emergency information about their child with special needs.

1308 BEST COPY AVAILABLE

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healthcare provider.

Gate 2: When there are changes in the child's health status, parents complete Gate 2, which they use to monitor further changes and decide whether they should call the physician.

Gate 3: They complete Gate 3 prior to calling the doctor, or other healthcare provider, so that they will have all the necessary information at hand. Gate 3 is a concise report of the events surrounding the child's current illness. This allows the parent to communicate more quickly and to have all the information the health provider will need to help make a decision about care.

Gate 4: If the child's status requires calling 911, parents complete Gate 4 after attending to the emergency.

The Gated Assessment is placed in a Daily Planner so that a permanent record of the child's health status is nested within a record of the family's daily activities. Placing the CHSA there increases the likelihood that parents will remember to do the assessment. It also helps parents see whether the child's status has been affected by family events.

Appendices

The Appendices include information that can serve as a handy reference and can include:

- Private Insurance Worksheet
- Measurement and Abbreviations Chart
- Metric Doses and Apothecary Equivalents
- Glossary of Commonly Encountered Medical Terms
- Resource Directory of commonly used phone numbers, contact information for community centers, and any useful local, state, and national organizations.

A major goal of the Parents as Partners in the Medical Home Project is to enable parents to serve as partners on their child's healthcare team. The CHSA is a critical tool in achieving this goal. Parents use the CHSA to upgrade their daily observations of their children into a portable, durable medical record. In effect, they are applying the scientific method—systematic observations—to the art of parenting. As a result, they find providers more likely to listen to them. Parents have reported that their children's physicians were surprised and pleased when parents could retrieve notes from previous discussions or plans of treatment. Said one parent: "I love the reaction from doctors; they are finally listening to me and looking at the data I collect." Another shares a similar experience: "I started writing what the doctor said at visits in the communication log. After three visits to the same doctor for the same problems, I was able to read back to the doctor what he said in previous visits. The doctor read my comments and for the first time acknowledged my concerns and

continued on page 110

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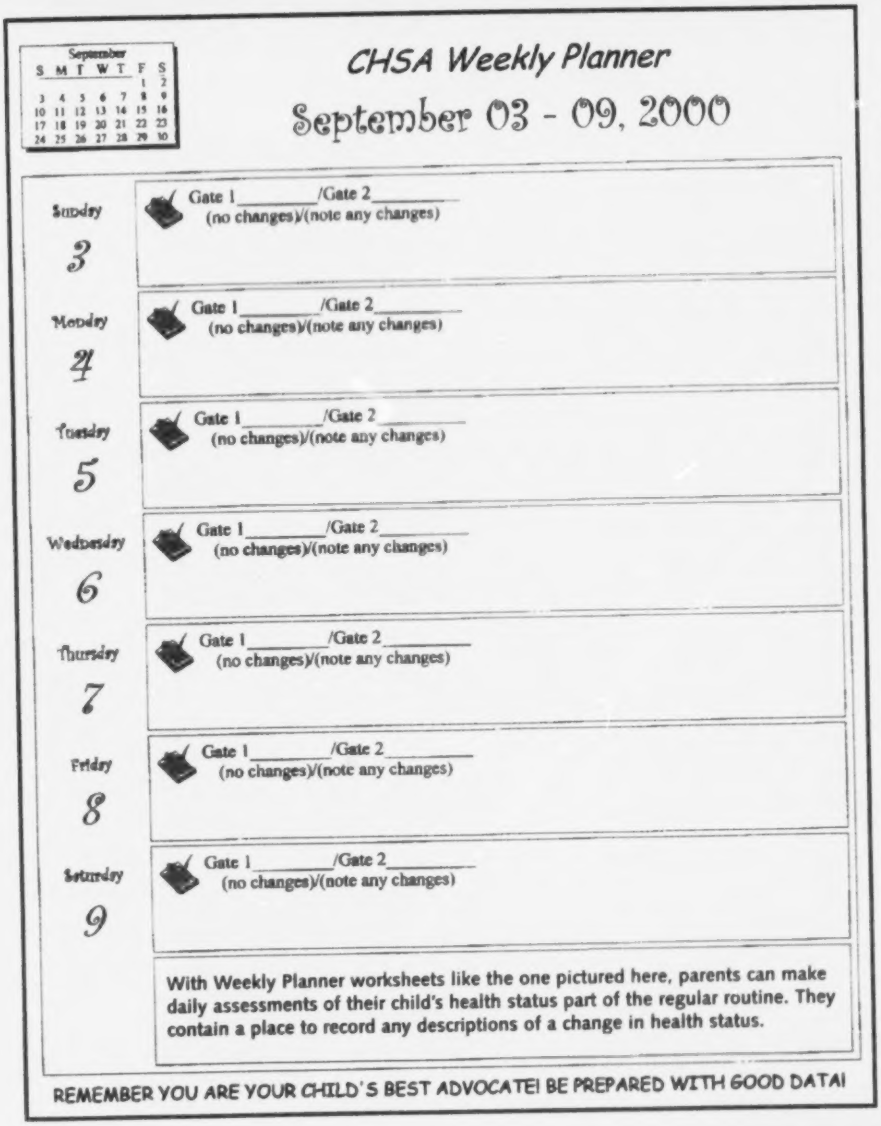
Circle #69

1309



September						
S	M	T	W	T	F	S
					1	2
3	4	5	6	7	8	9
10	11	12	13	14	15	16
17	18	19	20	21	22	23
24	25	26	27	28	29	30

CHSA Weekly Planner

September 03 - 09, 2000

Sunday 3
Gate 1________/Gate 2________
(no changes)/(note any changes)

Monday 4
Gate 1________/Gate 2________
(no changes)/(note any changes)

Tuesday 5
Gate 1________/Gate 2________
(no changes)/(note any changes)

Wednesday 6
Gate 1________/Gate 2________
(no changes)/(note any changes)

Thursday 7
Gate 1________/Gate 2________
(no changes)/(note any changes)

Friday 8
Gate 1________/Gate 2________
(no changes)/(note any changes)

Saturday 9
Gate 1________/Gate 2________
(no changes)/(note any changes)

With Weekly Planner worksheets like the one pictured here, parents can make daily assessments of their child's health status part of the regular routine. They contain a place to record any descriptions of a change in health status.

REMEMBER YOU ARE YOUR CHILD'S BEST ADVOCATE! BE PREPARED WITH GOOD DATA!

continued from page 109

tried a new medication to help my child. I was happy for my child and felt like the doctor finally listened."

Parents can use the CHSA:

- as a record to bring along to all child-related appointments;
- as a place to record what providers say during these appointments;
- to make notes during phone conversations (in the Logs section); and
- to file written correspondence.

Based on their recorded information, parents can anticipate problems earlier and may avoid the need for more radical treatments, such as visits to the emergency room or hospitalizations. Writing important information in a special place reduces the load on parents' memories (and those of the providers). Parents also found that the CHSA eased their stress in coordinating care from various providers and dealing with managed care systems. One parent reported: "The Communication Log helped in requesting a paid care attendant for my son." Further, by placing the CHSA in a daily planner, parents were able to see their children's special needs as part of the family's daily schedule. Families participating in the Parents as Partners in the Medical Home Project have welcomed the means to proactively participate in their children's healthcare. We invite all parents who are interested in participating in our study of the effectiveness of the CHSA to e-mail us at PTMEDHOME@aol.com or phone Karen Burstein at (480) 965-8619.

Tanis Bryan, PhD, and Karen Burstein, PhD, both special education faculty at Arizona State University, Tempe, are Co-principal investigators for the Medical Home Project Team.

Dr. Bryan brings extensive knowledge and experience in conducting community-based investigations to the team.

As a parent of a child with special healthcare needs and former CEO of a children's rehabilitation facility, Dr. Burstein brings extensive expertise on the problems of families and children as well as research design to the team.

Acknowledgements

We gratefully wish to acknowledge the participation of parents in the Improving Managed Care for Children with Chronic Health Care Needs Project. The study would not have been possible without the support and help of Sharon Attwood, Elli Bogden, Lisa Carlson, Sherry Charlot, Lela Chipman, Janet Churchward, Brad Geeck, John Gooch, Velma Leftwich, Jackue Marchosky, Angela Moberg, Mae Moore, Sandra Parker, Aura Rubin, Bonnie Rubio, Lori Sholtes, Esther Tanner, Leah Vincent, Darlene Watkins, Julie Webb, and Martha Young.

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Parents come and stay during the sessions and have the support of the other families. Quite often they share information, thoughts and feelings that can only be done with someone who walks in their shoes. Through play, during leisure time, the children form bonds which carry over into the class. This peer dynamics in the class helps us to generate a willingness to try new things and if one child is able to learn a new skill it helps to motivate the other children to try and copy them.

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For information and to receive a free video call: 1-800-442-6992 or www.abilitycamp.com

These are currently considered alternative therapies and investigational research as to their effectiveness and mechanisms are currently being conducted. Parents and professionals are encouraged to study the prevailing literature which we would be happy to provide or suggest.

Circle #17

Epilepsy Awareness Month

The Epilepsy Foundation of America is getting the word out about epilepsy and has designated November as Epilepsy Awareness month. Look for the following epilepsy coverage in the media during NOVEMBER.

- In addition to informational video releases to local television news stations and other anticipated television and Internet coverage, epilepsy content will be seen in the following media in November:
- *Journal for Women's Health*, November issue—Report on the Epilepsy Foundation's survey of medical practitioners' knowledge about health issues related to women.
- *USA Today*, November 10—A special supplement sponsored by the American Academy of Neurology will feature information about the major neurological disorders, including a section on epilepsy. The Epilepsy Foundation will be listed among resources for further information.
- Various media will contain reports on The Epilepsy Foundation's "Kids and Seizures: Know the Hidden Signs" campaign, which is focused on making parents and childcare providers aware of common but little-known signs of epilepsy in young children. The text of the "Kids and Seizures" pamphlet as well as information about Epilepsy Month, will be posted on the Foundation's Web site: http://www.efa.org, or contact them at:

Epilepsy Foundation
4351 Garden City Dr.
Landover, MD 20785
Phone: (800) 332-1000;
(301) 459-3700

Also in November, EP will be publishing a monograph, *Contemporary Issues in Epilepsy*, which will encompass new treatment therapies including some promising surgical interventions and new drug therapies. The publication is a follow-up to last year's award-winning monograph, *Epilepsy: New Patterns of Care for the Twenty-First Century*, and is sponsored once again by Elan Pharmaceuticals. Edited by Dr. Schlomo Shinnar of Albert Einstein School of Medicine, along with a blue ribbon panel of epileptologists, *Contemporary Issues in Epilepsy* will be available at the World Congress & Exposition on Disabilities in Atlanta on November 10-12, and will appear in the pages of EP in December.

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Circle #35

My Choice For My Life: Coming to terms with ADD

by Amy Wojtkielewicz

My name is Amy. I am a 15-year-old girl from Erie, Pennsylvania, and I have attention deficit disorder (ADD). Part of my treatment is working with Jennifer Girts, a counselor at the Achievement Center near my home. One afternoon when I was really frustrated, she gave me an article on ADD and adolescents. Wow! I loved it! It really helped me understand a lot about myself. Now I feel moved to write my own article telling my story: when I was diagnosed, the ways I felt about it then, and how I am coping now. Having dealt with ADD for nine years, I know how other kids with it feel. I was there at one time, too, and I hope my story will help.

Before we found out about ADD, my childhood was good. I have wonderful parents and a younger brother, Brian, who mean the world to me. I was good and bad, just like any other child. Then, in first grade, we found out I have ADD. My life changed from then on.

My parents had taken me to all different kinds of counselors because I had trouble paying attention in school and would lose my temper all the time. Sometimes I would be mad at my family for no reason—especially on school nights. I would pack my book bag and stomp out the front door. I remember one time when I was really angry and acting out, I walked out and my parents actually locked me out! I screamed really loud because I was really scared. Brian was very upset. I was only 6 years old! I can look back now and laugh. Over the years, I would do this kind of stuff to my parents. But they never gave up on me. They were always there for me when I needed them.

> **Listen, it's up to you. Its your choice; no one can force you to take your medicine. I know which person I would rather be. It was up to me to make the right choice.**

Coming to terms with ADD

When I first heard about ADD, I did not know what it was. I remember asking my parents about it. They explained it to me and I asked, "Will it ever go away?" The answer: "No." This made me really upset. They assured that me that ADD could be treated, but that I needed to want the help.

I was more than halfway through the first grade when we found out about my ADD. My parents made the decision to hold me back because of all the trouble I was having in school. To this day, I can remember the pain I felt when they told me I was going to repeat first grade. I was mad when they told me, and for a long time afterwards! Especially when school started again. I was always made fun of because I was older than the rest of the kids. I still get upset about being held back, and now and then, want to blame it on my parents. Sometimes I feel, "How could you do this to me? I thought you loved me. I hate you." Luckily, my family was always there for me. I don't know where I would be if they had ever given up on me.

Today, I realize that even if you have ADD, it doesn't make you different from anyone else. We are all people and we all matter in this world. Please, do not let anyone tell you different. If they do, don't believe them. I know what you are going through because I was once there myself or I still am. We are all the same: people who need love and understanding.

My parents thought bringing me to a psychiatrist, who could give me medication,

continued on page 118

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Amy Wojkielewicz knows how kids with ADD feel, and she wants to help by sharing her story.

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would help me. I thought I was going to lose my head trying all the different kinds of medications suggested. I ended up trying eight different kinds. Can you believe it? I took kinds that made me less hungry, some that made me depressed, and others that made me confused. Finally, my doctor found a combination that works. Now I am on Adderall and Clonidine.

Making a choice

Finally we found the right medication, but then I never wanted to take it. I would hide it in my dog's chew toys or put it up my sleeve. Now I find myself wondering why I would want to do that since the medication really does help me. My mom assures me there was a time when I didn't care if it did or not. Here is the real reason: I wanted to be normal. After all, no other kid I knew took medication. But when I did not take my medication, I always had difficulty paying attention, and my grades dropped. I was a grouch—definitely not a nice person—all because I did not take my medication.

Finally, my counselor said to me, "Amy, it is your choice to take your medication or not. A lot of people take medication for all different kinds of reasons. You need to decide if you want to be in control of your moods and impulsivity. What kind of person do you want to be: someone in control or a grouch?" I finally realized that I need the medication to help myself. That's the way my father put it. He would say, "You need to help yourself before you can help others."

Having dealt with ADD for seven years, I know how other kids with it feel. I was there at one time, too, and I hope my story will help.

Listen, it's up to you. It's your choice; no one can force you to take your medicine. I know which person I would rather be. It was up to me to make the right choice—not my parents or my counselor. Other people can ask me to take medication, but I need to be smart enough to realize that I need it. I found out that it was the best thing for me. So my advice to others is: be smart and take your medication. It will help you—take my word for it.

Now my life is pretty good. I am in the eighth grade. I make good grades and have tons of friends. I still take my medication every morning and at night. And I still see my counselor every once in a while. She helps me sort out my feelings and ask myself the right questions. But, hey, I have ADD. And I am normal.

Don't get me wrong, I still have my ups and downs—everyone does. It's not because of ADD; it's because I am human. My life has changed over the years. I've come to understand what ADD can mean to me. ADD may never go away, but I have the power to control it. I will not let it control me again. I have made my choice. The right choice. You have to decide how you want to live: as Oscar the Grouch, or as a person in control with a wonderful life. What is your choice?

Amy is an eighth grader at Walnut

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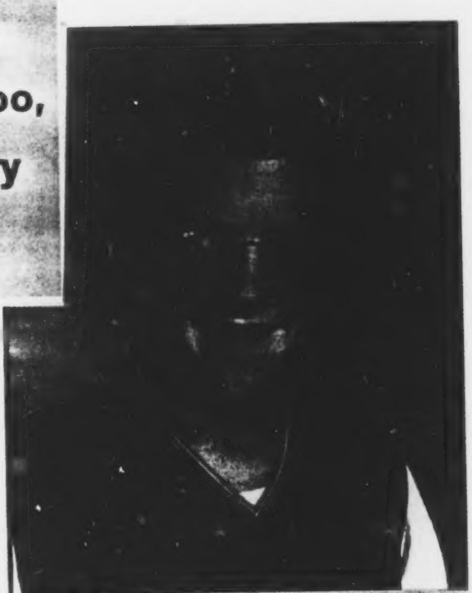

Brian, 13, Amy's younger brother, has come to understand ADD by learning about it with his sister.

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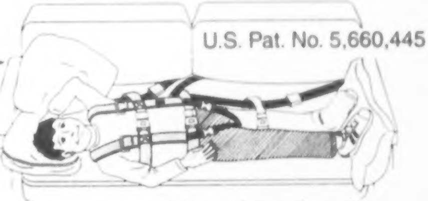

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Pointers for Parents

Get educated about attention deficit disorders.

Information—for you, your child with ADD, siblings, friends, teachers, extended families, and others—is a great ally for understanding, planning, and selecting treatment.

Don't go it alone.

Join CHADD or a support group for you or your children. ADD is hard on everyone; you don't have to feel so alone.

Look long as well as short range.

Children diagnosed with attention deficit disorders, as well as their siblings and friends, gain insight into themselves and treatment both with information and by growing older and maturing. What they may not be able to grasp today, could come easier with time.

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Creek School in Erie, Pennsylvania. Her favorite subject is English and favorite pastimes are hanging out with her friends, going to the mall, school dances, camping with her family, and helping other people. She wants to be a counselor for children with ADD. She enjoys talking with Jennifer Girts, her own counselor, and feels that it would benefit children with ADD to talk to a counselor who has had first-hand experience with the disorder.

From the Parents' Perspective

by J. Carlisle Spivey

Joe and Carol Wojtkielewicz learned to be advocates for their daughter by doing. Amy's first-grade teacher was the first to recognize that their 6-year-old was having trouble focusing and paying attention. Once she was tested, ADD was identified and Ritalin was suggested right away. Joe and Carol were reluctant at first. They wanted to know more about the disorder and what it meant for their daughter. First they turned to their pediatrician. They then discovered that he was less of an expert than he thought he was. They were not getting answers to their questions or concerns.

Disappointed, they sought out information from every possible place they could think to try, including the Internet. From information at the public library, they discovered CHADD—Children and Adults with Attention Deficit Disorder. Through CHADD, they found a children's book about ADD. With Amy, they sat down, read it, and talked about what this would mean to her.

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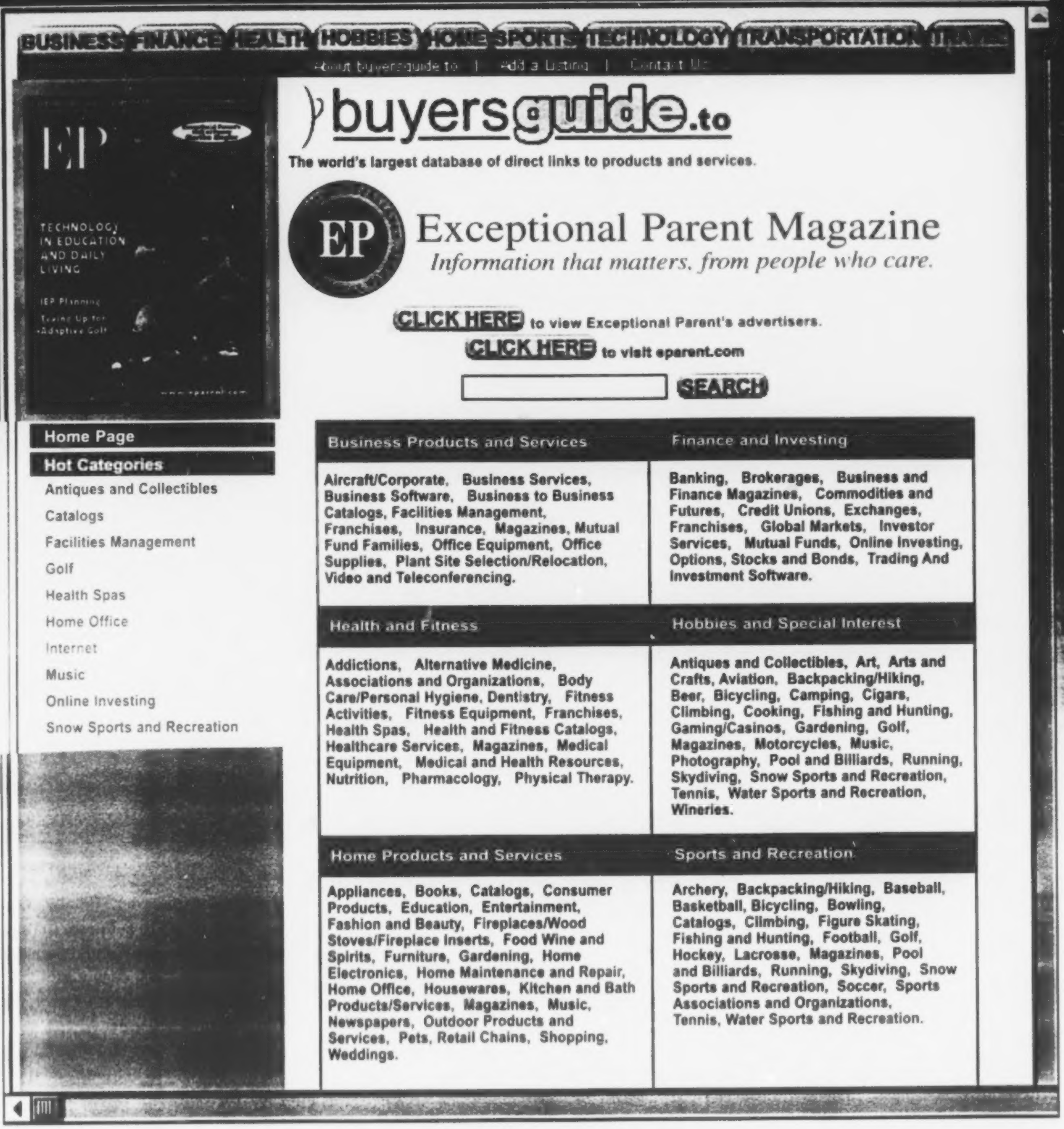

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When the Going Gets Tough, the Tough Get Support—CHADD provides families the support they need.

In 1987, few people knew about, much less understood, attention deficit disorder (also known as attention deficit-hyperactivity disorder or ADD/ADHD). That was the year that a group of parents in Florida with children with ADD/ADHD started a support group to help each other, their children, and their families understand and cope with their frustration and sense of isolation.

Thirteen years later, that support group has grown dramatically to become the leading non-profit national organization for children and adults with ADD/ADHD: CHADD—Children and Adults with Attention-Deficit/Hyperactivity Disorder. While the organization—now headquartered in Landover, Maryland (there is also a CHADD-Canada)—has a small national staff, it continues to be run by volunteers. And it has never lost the passion and commitment that launched what has become a major print, electronic, and one-on-one source of information, research studies, and support for people with ADD/ADHD.

One of the key purposes of CHADD is to provide advice and counsel for parents of children with disabilities. Following are frequently asked questions for which CHADD has tried to provide helpful and practical answers for parents in communities around the country.

CHADD
8181 Professional Place
Ste. 201
Landover, MD 20785
Phone: (800) 233-4050;
(301) 306-7070
E-mail: national@CHADD.org
Web site: http://www.Chadd.org

continued from page 120

They have also had to explain ADD to members of their extended family. With an understanding of how the disorder affects behavior and learning, the family have been very supportive.

Understanding ADD has come to both Amy and her brother, Brian, as they have learned more about it. Some of this has come with simply getting older and maturing. "We explained it to Brian the best we could at his age," explains Carol. "He really did not understand at that time what ADD was. All he knew was that Amy took medicine every day." Now that he is older, he can grasp what ADD is. "Amy and Brian are very close," Carol is happy to report. "It is hard on him sometimes when she is grouchy at the family or says something hurtful. But then it is all better when she says that she is sorry."

While they admit that it can be frustrating always having to remember that ADD is influencing Amy, Joe and Carol have tried to take the approach of supporting and encouraging her in whatever she has undertaken. "We also have to understand Brian, and help him deal with things when they get tough because of Amy," Carol notes. "It is not always easy, but you ask God to help you every day and to help your child." The number one thing, she emphasizes, "is to love your child and remember that she or he did not ask for this condition." Carol also points out that it is critical for parents to get as much knowledge about ADD/ADHD as they can. Joining a support group for parents and siblings—ADD is hard on the whole family—will help combat the feeling of being alone in dealing with the disorder. Finally, Carol advises other parents to get more than one opinion about treatment and counseling for their child. "We have seen a lot of doctors and counselors," asserts Carol, "the ones Amy has now are great."

Carol and Joe have fought hard to understand ADD and to help Amy deal with it and to develop her own successful approach to the disorder. They credit their commitment to and reliance on one another for the success their family has had in doing so. ■

Joe Wojtkielewicz is a purchaser/ buyer for the Erie Daily Times newspaper. Carol is a secretary for a private investigator.

J. Carlisle Spivey is a freelance writer based in Connecticut and a frequent contributor to EP.

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organizational spotlight

continued from page 78

There are no other entities in our society that rise to the task of giving voice and taking action on behalf of the millions of people living with genetic disorders. The Genetic Alliance sees its mission as walking hand in hand with lay advocacy organizations, offering resources and assistance when needed, creating synergies between groups, and respecting the uniqueness of each group's challenges and solutions.

Health Professional Education—HuGEM and Partnership Program

The Human Genome Education Model Project II (HuGEM II), in collaboration with Georgetown University, works with the leadership of seven national health professional associations to enhance understanding of the genetic service needs of their clients. The Partnership for Genetic Services Pilot Program raises the awareness of health professionals, who are in training in medical, nursing, and physician assistant schools and in practice in managed care and other clinical settings. They bring attention to the unique needs and resources of affected individuals and their families.

Public Policy—Consumer Voices Network (Network)

The Alliance voices the common ethical, legal, and social concerns of families, lay advocacy groups, and professional members. It represents consumer issues with policymakers and the newsmedia as well. The Consumer Voices Network is grounded on a core Alliance guiding principle: "Meaningful progress in research, policy, and legislation requires consumer involvement." Members are informed and kept up-to-date through newsletters, e-mail 'legislative links,' and Web site postings.

Realization of the promise

The annual membership meeting embodies the essence of the Genetic Alliance. One look around the room and you know the power of the Genetic Alliance lies in the power of family—in the power of being heard. And you know that as we walk our own special journey, we are empowered by one another's story. The Genetic Alliance provides the crossroads; we need only to visit, speak and be heard. ■

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familiar faces

ZACHARY

Zachary Tawadros, 3, looks ready for anything! According to his mom, Deborah, Zachary had a rough first few years. He has been diagnosed with microcephaly, mild cerebral palsy, developmental delays, verbal apraxia, and numerous respiratory difficulties. He enjoys playing with balls, making Lego towers, and watching his older brothers, Vicktor, 9, and Gabriel, 6, play Nintendo. The three boys live with their mom, dad, Sam, and sister, Cassandra, 4, in Ocoee, FL.

CHRISTOPHER

Love those eyes! **Christopher Rosenberg,** 10, has cerebral palsy and a seizure disorder. He has a vagus nerve stimulator to control seizures and a trach tube. Chris attends school in Queens, NY. He loves food and music, and also enjoys going for rides in the car. Chris lives with his parents, Connie and Stuart, in Bayside, NY.

KENNEDY

Kennedy Joy Stafford, 3, is a real swinger! This picture was taken when Kennedy was 20-months old. Kennedy has Down syndrome and attends a toddler group that also includes physical and occupational therapies. She loves going to school, reading her books, dancing, riding in her wagon, playing with Alex (the family cat), and of course, swinging in her backyard. Kennedy lives with her parents, Billy and Shannon, in Council Bluffs, IA.

Would you like to share a favorite candid snapshot or slide of your child and/or family with other readers of Exceptional Parent? Send it to: Readers' Photos, *Exceptional Parent*, 555 Kinderkamack Road, Oradell, NJ 07649-1517. (Please do not send originals or "one-of-a-kinds" as we regret that **photos cannot be**

KAITLYN & JORDAN

Kaitlyn, 6, and **Jordan Pringle**, 5 months, put their heads together! Both children were born with Down syndrome. Kaitlyn attends a full-inclusion kindergarten and has a vocabulary of about 130 words. She loves to swim, dance, and sing. Jordan has just begun occupational therapy. According to their mom, Mary, Jordan rolled over at 3 weeks and seems to be "right on target." The two children have seven siblings: Mandie, 20; Michelle, 19; Korey, 18; Erin, 17; Joshua, 11; Kirsten, 6; and Steven, 3 (who also has Down syndrome). They live with their mom and dad, Clarence, in Cape Coral, FL.

ANDREW

Grab your sunglasses! According to his mom, Marilyn, **Andrew Brettner**, 4, "has a great smile that just lights up a room." Andrew, who has cerebral palsy, was born at 27 weeks and weighed 2 lbs. 9 oz. Andrew enjoys trucks more than anything, and likes visiting construction sites with his dad, Chris, whenever he can. His mom describes him as "a real people person." He has one stepsister, Jackie, who is 20. Andrew and his parents live in St. Petersburg, FL.

TAYLOR

Taylor Zesiger, 7, gives a big smile for her kindergarten portrait, taken when she was 6. Taylor has Williams syndrome (a rare congenital disorder that can result in exceptionally sensitive hearing, developmental delays, cardiovascular anomalies, and high blood levels of calcium). She is mainstreamed in school and loves horses and being around people. Her mom, Jane, says, "She's my social butterfly." Taylor and her mom live in Keystone, SD.

returned.) On a separate sheet of paper, write your child's full name, age at the time the photo was taken, address and daytime phone number. Please identify everyone in the photo. If you like, you can also write a few sentences about your child. Then look for a familiar face in an upcoming issue!

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I certify that the statements made by me above are correct and complete.

—Joseph M. Valenzano, Jr., Publisher

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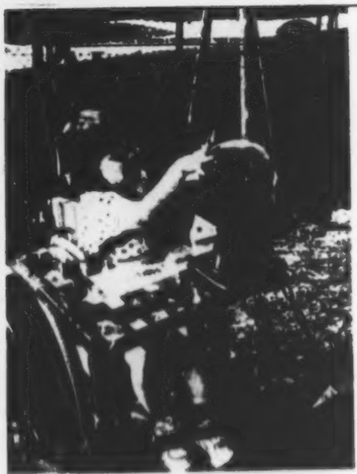

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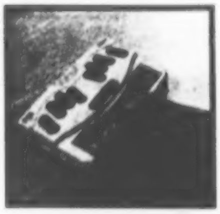

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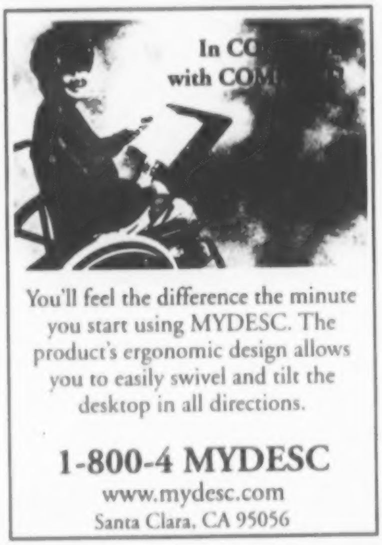

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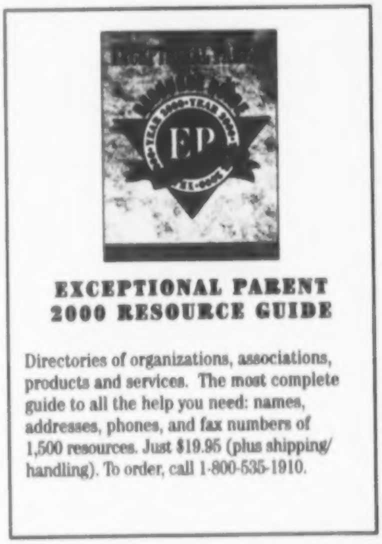

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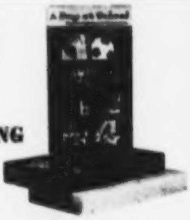

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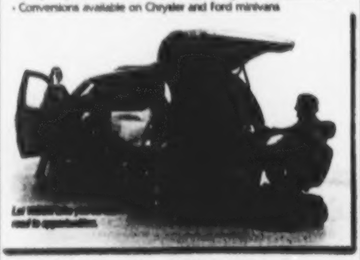

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My Friend and Me

by Kelly Foran Schmidt

My friend and me, we both have CP;
I need help to walk, she needs help to talk.

I have a walker, and she has a talker.

A little girl once said I was so lucky to ride the elevator
because she had to use the stairs,
but I thought that she was lucky to have the freedom to walk
without a wheelchair.

My friend can't use words to tell us how she feels;
at her favorite part of movies she squeals.

She uses a picture board to tell people what she thinks;
one picture on the board tells people what she wants to drink.

If I want pudding, a brownie, or a slice of cake,
I ask using my mouth or I just take.

My friend and me both use wheelchairs to get around;
in the summertime, at Cape May, we both can be found.

I really like my friend.

A day on the boardwalk in Wildwood, NJ. Clockwise from upper left: family friend, Melanie, Megan, Tara's parents, Stephen Stern and Laura Siegel, Tara, Tara's sister Samantha, 6, Sarah, and Kelly.

My friend's name is Tara. She's 10 years old and, like me, lives in Manhattan. My family spends two weeks with Tara's family in Cape May, New Jersey, each summer. We like to go swimming in the pool, and we also like crabbing, where we put fish heads or tails in crab traps, put the traps in the water, and wait for the crabs! We also go to Wildwood, New Jersey, which is a town near Cape May. There they have a pier and rides. I like the Crazy Bus ride. I also see Tara at her birthday parties in New York.

Kelly lives with her father and mother, David Schmidt and Peggy Foran, and two older sisters, Megan, 14, and Sarah, 12. ■

DAD'S TURN

Kelly's father is impressed by his daughter's outlook on life. "I have always found Kelly's approach to life amazing. She rarely dwells on her disability and what she can't do, and instead focuses on what she can. What's been particularly rewarding to see has been how Kelly reacts to the many challenges she faces. She does so with a very positive, upbeat, 'can do' attitude, which I think has been a key component in her successes to date."

Making friends seems to be one of Kelly's strong suits as well. "She has friends, both with and without disabilities," continues Mr. Schmidt, "and enjoys playing with all of them. She's a very verbal child and uses this to her advantage by being outgoing and drawing people (both adults and children) to her."

The Children's Page welcomes contributions from children who have disabilities, their siblings, and their friends. Be creative! Send your stories, photos and/or artwork to: Children's Page, Exceptional Parent, 555 Kinderkamack Road, Oradell, NJ 07649-1517. Be sure to include your name, address, and daytime telephone number! Now on the Web! We will now be including **Familiar Faces** and **Children's Page** on our Web site, www.eparent.com. Please send us your photographs with the understanding that doing so gives Exceptional Parent permission to put the photos on the Exceptional Parent Web site, exactly as they appear in the magazine and with the same text.

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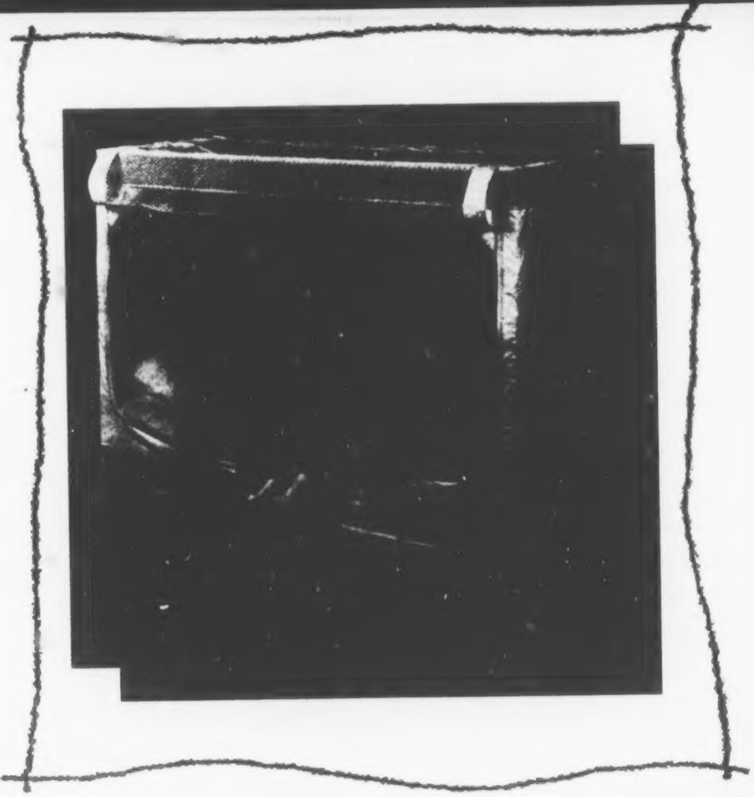
A Better Bedtime Story

The Vail Enclosed Bed



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CAN YOU FIND THE SYMPTOMS OF CARNITINE DEFICIENCY IN THIS PICTURE?

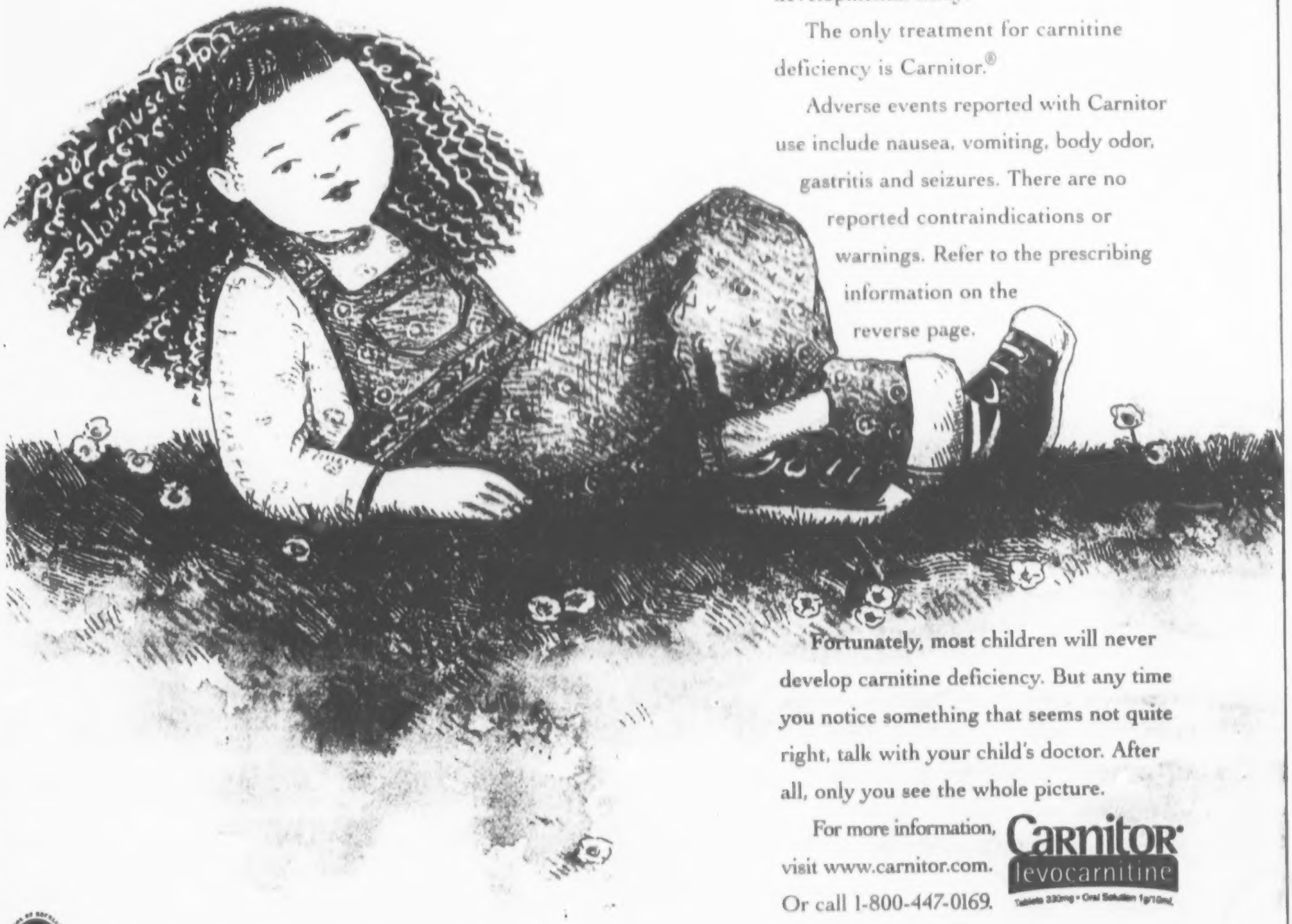
No one knows your child as well as you do. So no one's better at seeing the subtle things that affect your child's health. Things like carnitine deficiency.

Carnitine is a naturally occurring substance that's essential in the metabolic process. If the body is deficient in carnitine, the ability of the cells to produce energy and to remove toxic wastes is impaired. And while carnitine deficiency can be serious, its symptoms are hard to detect and are often overlooked.

Signs include muscle weakness, frequent infection, seizures, poor muscle tone, slow growth, speech difficulties, slow weight gain, lack of energy and developmental delay.

The only treatment for carnitine deficiency is Carnitor.®

Adverse events reported with Carnitor use include nausea, vomiting, body odor, gastritis and seizures. There are no reported contraindications or warnings. Refer to the prescribing information on the reverse page.



Fortunately, most children will never develop carnitine deficiency. But any time you notice something that seems not quite right, talk with your child's doctor. After all, only you see the whole picture.

For more information, visit www.carnitor.com. Or call 1-800-447-0169.

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BRIEF SUMMARY

The following is a brief summary. Please see package insert for full prescribing information.

CLINICAL PHARMACOLOGY

CARNITOR® (levocarnitine) is a naturally occurring substance required in mammalian energy metabolism. It has been shown to facilitate long-chain fatty acid entry into cellular mitochondria, therefore delivering substrate for oxidation and subsequent energy production. Fatty acids are utilized as an energy substrate in all tissues except the brain. In skeletal and cardiac muscle they serve as major fuel. Primary systemic carnitine deficiency is characterized by low plasma, RBC, and/or tissue levels. It has not been possible to determine which symptoms are due to carnitine deficiency and which are due to the underlying organic acidemia, as symptoms of both abnormalities may be expected to improve with carnitine. The literature reports that carnitine can promote the excretion of excess organic or fatty acids in patients with defects in fatty acid metabolism and/or specific organic acidopathies that bioaccumulate acyl CoA esters.

Secondary levocarnitine deficiency can be a consequence of inborn errors of metabolism. CARNITOR® may alleviate the metabolic abnormalities of patients with inborn errors that result in accumulation of toxic organic acids. Conditions for which this effect was demonstrated are: glutaric aciduria II, methyl malonic aciduria, propionic acidemia, and medium chain fatty acyl CoA dehydrogenase deficiency. Autointoxication occurs in these patients due to the accumulations of acyl CoA compounds that disrupt intermediary metabolism. The subsequent hydrolysis of the acyl CoA compound to its free acid results in acidosis that can be life threatening. Levocarnitine clears the acyl CoA compound by formation of acyl carnitine which is quickly excreted.

Levocarnitine deficiency is defined biochemically as abnormally low plasma levels of free carnitine, (less than 20 µmol/L at one week post term) and may be associated with low tissue and/or urine levels. Further, this condition may be associated with a ratio of plasma ester/free levocarnitine levels greater than 0.4 or abnormally elevated levels of esterified levocarnitine in the urine. In premature infants and newborns, secondary deficiency is defined as plasma free levocarnitine levels below age related normal levels.

BIOAVAILABILITY/PHARMACOKINETICS

In a relative bioavailability study in 15 healthy adult male volunteers CARNITOR® Tablets were found to be bio-equivalent to CARNITOR® Oral Solution. Following the administration of 1980 mg b.i.d., the maximum plasma concentration level (C_{max}) was 80 nmol/mL and the time to maximum concentration (T_{max}) occurred at 3.3 hours. There were no significant differences for AUC and urinary excretion observed between these two formulations.

In the same bioavailability study of 15 healthy adult males, CARNITOR® (levocarnitine) Injection administered as a slow 3 minute bolus intravenous injection at a dose of 20 mg/kg showed that free levocarnitine plasma profiles are best fit by a two compartment model. Approximately 76% of free levocarnitine is eliminated in the urine. Using plasma levels uncorrected for endogenous levocarnitine, the mean distribution half life was 0.585 hours and the mean apparent terminal elimination half life was 17.4 hours following a single intravenous dose.

The absolute bioavailability of L-carnitine from CARNITOR® Tablets and Oral Solution was determined compared to the bioavailability of L-carnitine from CARNITOR® Injection Intravenous in 15 healthy male volunteers. After correction for circulating endogenous levels of L-carnitine in the plasma, absolute bioavailability was 15.1% ± 5.3% for L-carnitine from CARNITOR® Tablets and 15.9% ± 4.9% from the Oral Solution.

Total body clearance of L-carnitine (Dose/AUC including endogenous baseline levels) was a mean of 4.00 L/hr. Endogenous baseline levels were not subtracted since total body clearance of L-carnitine does not distinguish between exogenous sources of L-carnitine and endogenously synthesized L-carnitine. Volume of distribution of the intravenously administered dose above baseline endogenous levels was calculated to be a mean of 29.0 L ± 7.1 L (approximately 0.39 L/kg) which is an underestimate of the true volume of distribution since plasma L-carnitine is known to equilibrate slowly with, for instance, muscle L-carnitine.

L-carnitine was not bound to plasma protein or albumin when tested at any concentration or with any species including the human.

INDICATIONS AND USAGE

CARNITOR® (levocarnitine) is indicated in the treatment of primary systemic carnitine deficiency. In the reported cases, the clinical presentation consisted of recurrent episodes of Reye-like encephalopathy, hypoketotic hypoglycemia, and/or cardiomyopathy. Associated symptoms included hypotonia, muscle weakness and failure to thrive. A diagnosis of primary carnitine deficiency requires that serum, red cell and/or tissue carnitine levels be low and that the patient does not have a primary defect in fatty acid or organic acid oxidation (see Clinical Pharmacology). In some patients, particularly those presenting with cardiomyopathy, carnitine supplementation rapidly alleviated signs and symptoms. Treatment should include, in addition to carnitine, supportive and other therapy as indicated by the condition of the patient.

CARNITOR® (levocarnitine) is also indicated for acute and chronic treatment of patients with an inborn error of metabolism that results in a secondary carnitine deficiency.

CONTRAINDICATIONS

None known.

WARNINGS

None.

PRECAUTIONS

General

CARNITOR® (levocarnitine) Oral Solution is for oral/internal use only.

Not for parenteral use.

Gastrointestinal reactions may result from too rapid consumption of carnitine. CARNITOR® (levocarnitine) Oral Solution may be consumed alone, or dissolved in drinks or other liquid foods to reduce taste fatigue. It should be consumed slowly and doses should be spaced evenly throughout the day to maximize tolerance.

Carcinogenesis, mutagenesis, impairment of fertility

Mutagenicity tests performed in *Salmonella typhimurium*, *Saccharomyces cerevisiae*, and *Schizosaccharomyces pombe* indicate that CARNITOR® (levocarnitine) is not mutagenic. Long-term animal studies have not been conducted to evaluate the carcinogenicity of the compound.

PREGNANCY

Pregnancy Category B.

Reproductive studies have been performed in rats and rabbits at doses up to 3.8 times the human dose on the basis of surface area and have revealed no evidence of impaired fertility or harm to the fetus due to CARNITOR®. There are, however, no adequate and well controlled studies in pregnant women. Because animal reproduction studies are not always predictive of human response, this drug should be used during pregnancy only if clearly needed.

NURSING MOTHERS

It is not known whether this drug is excreted in human milk. Because many drugs are excreted in human milk, a decision should be made whether to discontinue nursing or to discontinue the drug, taking into account the importance of the drug to the mother.

PEDIATRIC USE

See Dosage and Administration.

ADVERSE REACTIONS

Various mild gastrointestinal complaints have been reported during the long-term administration of oral L- or D,L-carnitine; these include transient nausea and vomiting, abdominal cramps, and diarrhea. Mild myasthenia has been described only in uremic patients receiving D,L-carnitine. Gastrointestinal adverse reactions with CARNITOR® (levocarnitine) Oral Solution dissolved in liquids might be avoided by a slow consumption of the solution or by a greater dilution. Decreasing the dosage often diminishes or eliminates drug-related patient body odor or gastrointestinal symptoms when present. Tolerance should be monitored very closely during the first week of administration, and after any dosage increases.

Seizures have been reported to occur in patients with or without pre-existing seizure activity receiving either oral or intravenous levocarnitine. In patients with pre-existing seizure activity, an increase in seizure frequency and/or severity has been reported.

OVERDOSAGE

There have been no reports of toxicity from carnitine overdosage. The oral LD_{50} of levocarnitine in mice is 19.2 g/kg. Carnitine may cause diarrhea. Overdosage should be treated with supportive care.

DOSAGE AND ADMINISTRATION

CARNITOR® (levocarnitine) Tablets.

Adults: The recommended oral dosage for adults is 990 mg two or three times a day using the 330 mg tablets, depending on clinical response.

Infants and children: The recommended oral dosage for infants and children is between 50 and 100 mg/kg/day in divided doses, with a maximum of 3 g/day. Dosage should begin at 50 mg/kg/day. The exact dosage will depend on clinical response.

Monitoring should include periodic blood chemistries, vital signs, plasma carnitine concentrations and overall clinical condition.

CARNITOR® (levocarnitine) Oral Solution.
For oral use only. **Not for parenteral use.**

Adults: The recommended dosage of levocarnitine is 1 to 3 g/day for a 50 kg subject, which is equivalent to 10 to 30 mL/day of CARNITOR® (levocarnitine) Oral Solution. Higher doses should be administered only with caution and only where clinical and biochemical considerations make it seem likely that higher doses will be of benefit. Dosage should start at 1 g/day, (10 mL/day), and be increased slowly while assessing tolerance and therapeutic response. Monitoring should include periodic blood chemistries, vital signs, plasma carnitine concentrations, and overall clinical condition.

Infants and children: The recommended dosage of levocarnitine is 50 to 100 mg/kg/day which is equivalent to 0.5 mL/kg/day CARNITOR® (levocarnitine) Oral Solution. Higher doses should be administered only with caution and only where clinical and biochemical considerations make it seem likely that higher doses will be of benefit. Dosage should start at 50 mg/kg/day, and be increased slowly to a maximum of 3 g/day (30 mL/day) while assessing tolerance and therapeutic response. Monitoring should include periodic blood chemistries, vital signs, plasma carnitine concentrations, and overall clinical condition.

CARNITOR® (levocarnitine) Oral Solution may be consumed alone or dissolved in drink or other liquid food. Doses should be spaced evenly throughout the day (every three or four hours) preferably during or following meals and should be consumed slowly in order to maximize tolerance.

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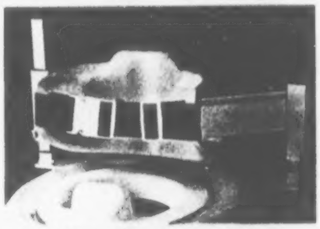

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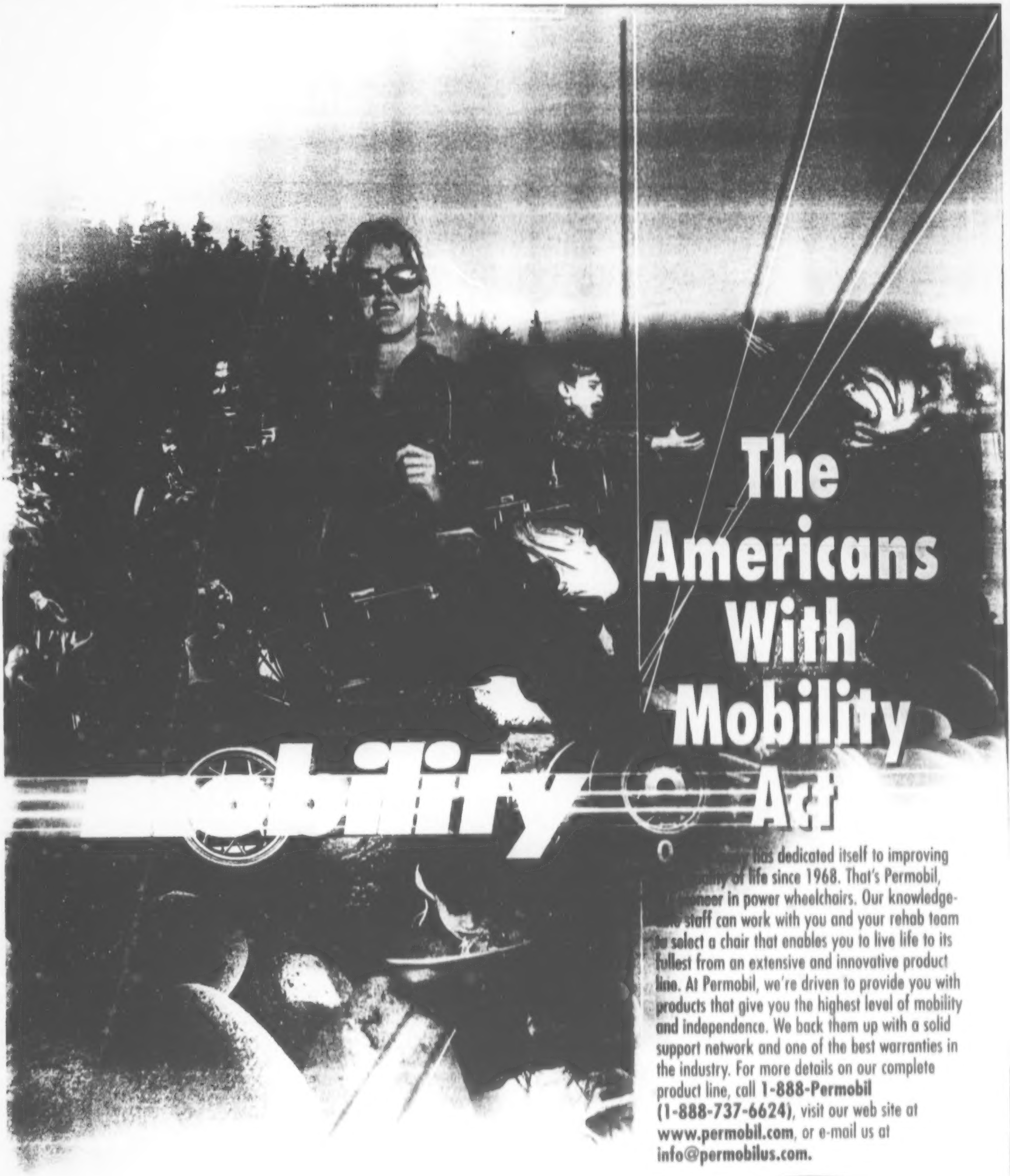

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DECEMBER 2000 • VOLUME 30, ISSUE 12

FAMILY, FRIENDS, & THE COMMUNITY

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PHOTO BY RHONDA CARROLL PHOTOGRAPHY

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EDITORIAL MISSION

- TO REACH OUT TO MOTHERS AND FATHERS OF CHILDREN AND YOUNG ADULTS WHO HAVE DISABILITIES AND SPECIAL HEALTHCARE NEEDS.
- TO EMPOWER PARENTS AND PROFESSIONALS BY PROVIDING PRACTICAL INFORMATION AND EMOTIONAL SUPPORT.
- TO APPRECIATE THAT PARENTS ARE THE MOST IMPORTANT EXPERTS IN THE LIVES OF THEIR CHILDREN.
- TO ENERGIZE PARENTS AND PROFESSIONALS.
- TO SHARE IDEAS AND EXPERIENCES SO PARENTS, PROFESSIONALS, PEOPLE WHO HAVE DISABILITIES, AND OTHER ADVOCATES CAN LEARN FROM ONE ANOTHER AND BETTER COLLABORATE TO SERVE ALL CHILDREN AND FAMILIES.

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MPA

For subscription and advertising information, see page90

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Circle #38

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WHAT LOVE HAS TO DO WITH IT

In last month's Editor's Desk, my first as Editor-in-Chief, I offered EP readers a disclaimer about myself. I thought it was appropriate to indicate that I am not a parent. I thought it would be of interest because it would always be apparent that my perspective, my reference point, will always be different from parents. Perhaps there would be a convergence of thought, but if so, it would probably be achieved through different pathways, certainly from different experiences. One area where this comes to bear is in my mystification and awe of the essence of "unconditional love." This unique and special love, intrinsic and automatic to parenting, is unlikely to be experienced outside the parent-child connection. It perhaps may only exist—may only need to exist—in that context.

Rick with his mentor, Chantel Leak.

Unconditional love, and I guess its antithesis, "conditional love," are seemingly like attendees at a thirty-year high school reunion. They've seemingly come from the same place, but no longer look the same, act the same, or even have much to say to each other after the first ten minutes. Like the neurogenic origins of tears of joy and sorrow, unconditional and conditional love have different missions, goals, and outcomes.

Unconditional love serves a purpose. It is automatic, instantaneous, cross cultural, timeless, energizing, involuntary, and engineered for the perpetuation of the species. Interestingly enough, the same can be said about the stress adaptation reaction. In "Journey of the Heart," John Wellwood writes, "When our child is born we do not have to decide to love this infant—the feeling is choiceless, and flows forth freely." Not fully appreciating this "choiceless" love, I asked my colleague Claudette Cox, who is also the parent of an adult with special healthcare needs, for her thoughts on what she makes of this "unconditional love thing" and how it has played a part in her caring for her daughter Donna. I was hoping Claudette would straighten me out but instead she ratchets up my confusion by offering, "Oh, you mean like agape love." Feeling like a real undergraduate in the subject of love, I admitted my ignorance. But it sounded like a great Scrabble word to boot. This agape (pronounced a - gape- hay) love is the type of love you feel when you are in a state of wonder; it's the kind that strikes you as an intense emotional reaction. Claudette went on to explain it's the type of unconditional love you extend to everyone, not just your children. To me it didn't compute, and so I found myself back with Wellwood.

"Moments of unconditional love allow us to touch the vastness and depth of human experience altogether."

It is unconditional love that parents employ, rely on, and draw strength from that allows them to weather the years of diligence and sacrifice. It is the kind of love I regretfully had never experienced. I came close. Call it a sighting. Several years ago I attended the Exceptional Parent Forum in California. The place was teeming with parents, their children, therapists, teachers, and physicians. I walked over to the play area and wham—there she was. I didn't know who she was but I was ready to take care of her forever. I instinctively dropped to the ground and started to play ball with her; it was magic. There was this spark.

Chantel is from Temecula, California. She remains to me the neatest kid I ever met. We've been friends ever since. Chantel's mom, Shirley Leak, declined my offer to take her home with me. She and her husband Tony and their two boys have gotten the "caring for Chantel" down pretty well after all these years. Chantel has a host of special healthcare needs though I'm not sure what they are. The beauty of my meeting Chantel was that it wasn't prefaced by my reviewing growth charts, functional assessments, or Vineland Adaptive Behavior Scales. It was just us meeting and playing on the floor, and that's all it took to cement it. I owe Chantel the privilege of experiencing (if only as a nibble) this thing that had eluded me. Maybe there is something to this unconditional love thing. After all, five million exceptional parents can't be wrong.

Rick Rader, MD

Rick Rader, MD
Editor-in-Chief

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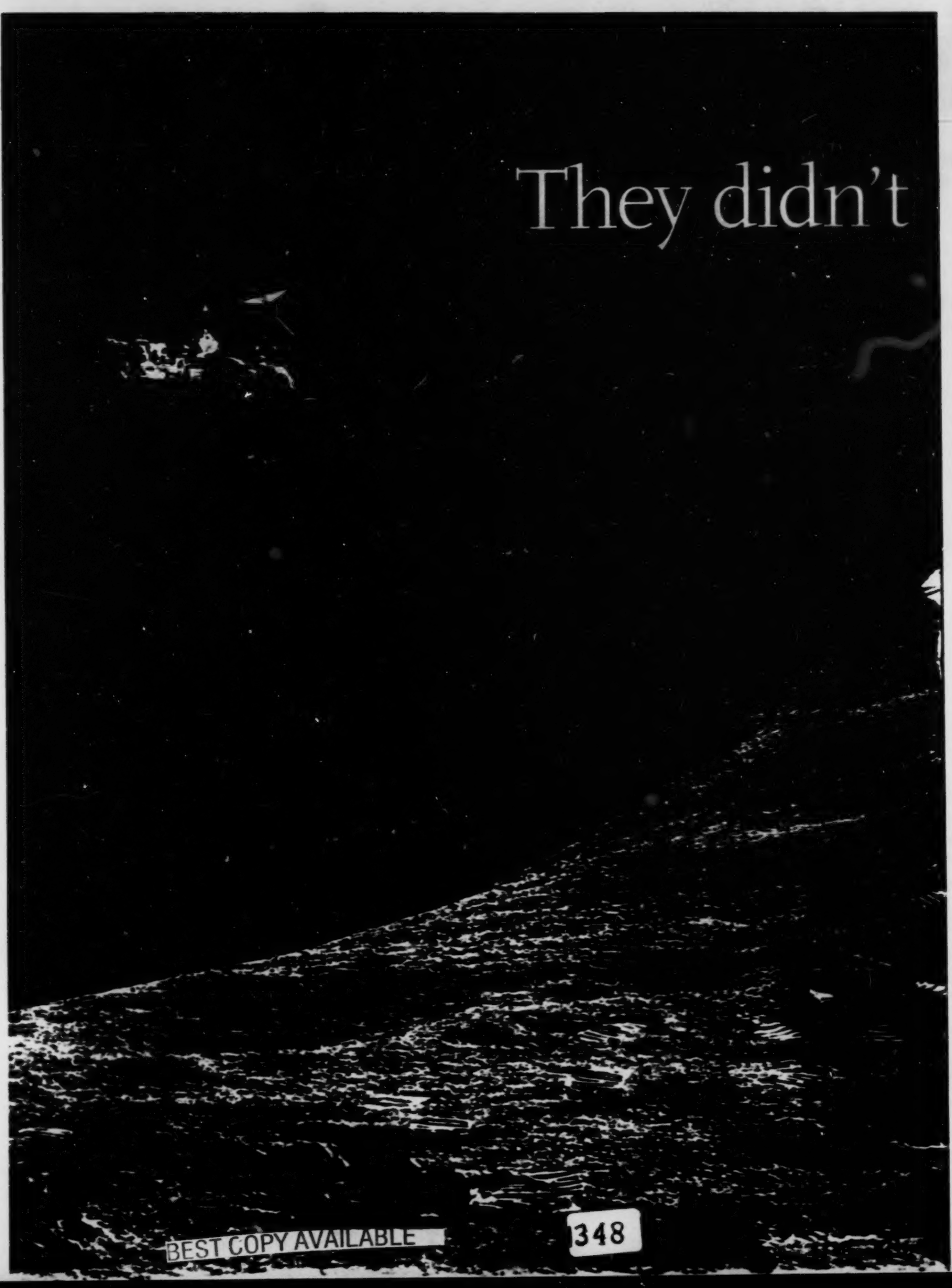

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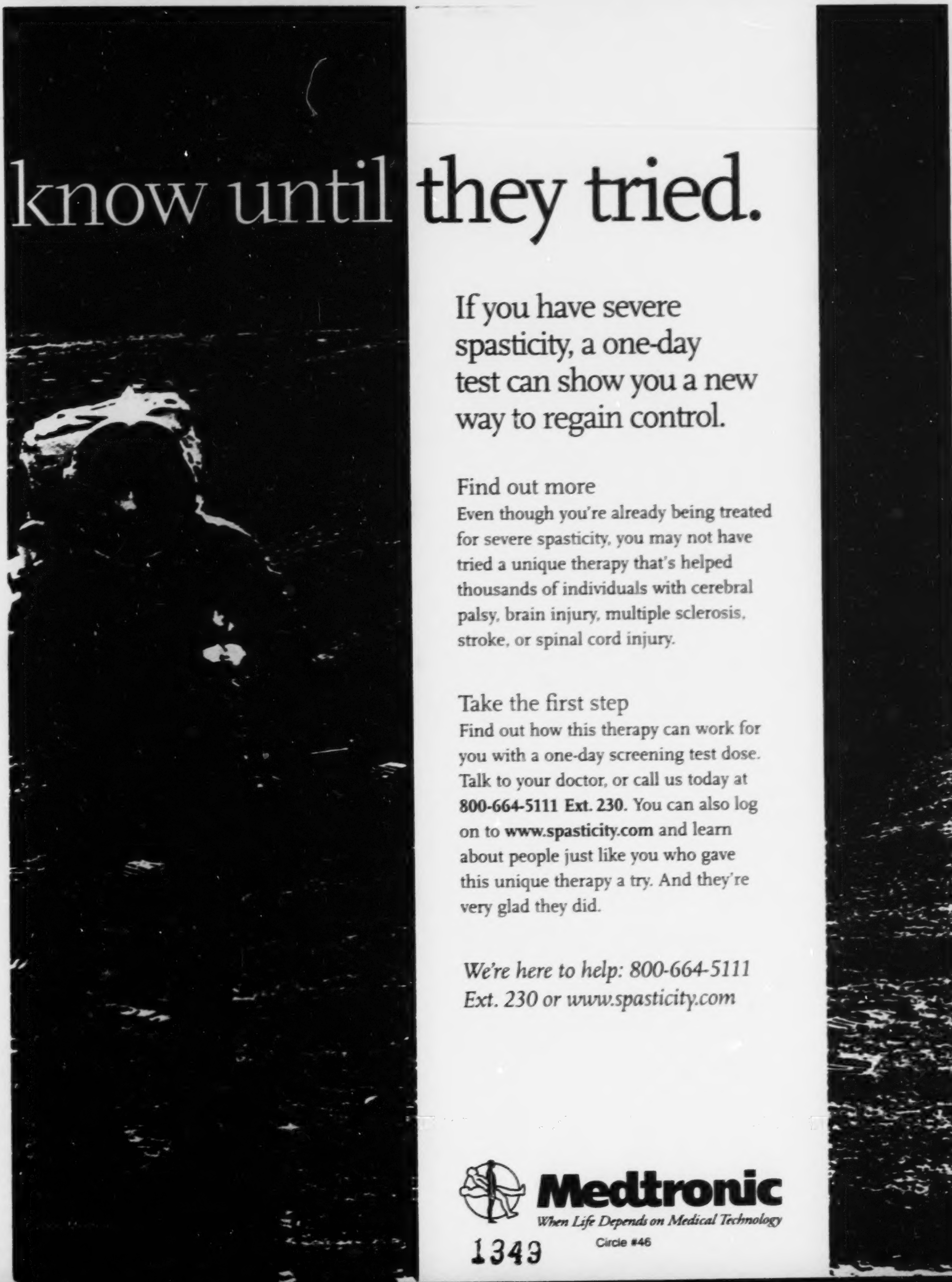

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Search & Respond

About Search & Respond

Search and Respond is an opportunity for our readers to exchange information about their practical experiences in meeting the everyday challenges of life with a child or adolescent who has a disability. In this column, "S" represents Search letters and "R" represents Respond letters received to a previously printed Search. "Instant S&R" is a new feature which represents e-correspondence we have downloaded from our Web site. All Responds are forwarded to the writers of the original Searches; some are published. Published letters may be edited for purposes of space and clarity. We also expect parents to consult appropriate professionals.

When sending correspondence, please indicate whether it is a Search or a Respond. For Responds, be sure to note in which issue the original Search letter appeared. Please remember to include a phone number on all correspondence, in the event that more information is required. Write to: Exceptional Parent, Attn: Search/Respond, 555 Kinderkamack Rd., Oradell, NJ 07649-1517; Fax to: (201) 634-6570; E-mail to epedit@aol.com; or visit Search and Respond on our Web Site: http://www.eparent.com.

For information about specific disabilities, contact: the National Organization for Rare Disorders (NORD), 100 Rt. 37, PO Box 8923, New Fairfield, CT 06812; (800) 999-6673; (203) 746-6518; Web site: http://www.rarediseases.org. Also, see the "National Resources for Specific Disabilities" directory in Exceptional Parent's 2000 Resource Guide (January 2000, starting on page 30).

Each month, Chris Feudtner, MD, PhD, reviews Search & Respond for accuracy and completeness. Dr. Feudtner is a pediatrician at the Pediatric Care Center of the University of Washington in Seattle, and is currently a Robert Wood Johnson Clinical Scholar. Look for Dr. Feudtner's comments on certain Search & Respond letters.

S

Need an adaptive high chair

My 3-year-old who has cerebral palsy (mild spastic diplegia) has outgrown his portable baby high chair. At restaurants, his legs cannot fit into the regular high chairs, and the booster seats are not secure enough for him to move and feed himself at the table. I am searching for a portable high chair that has the right seat depth to support his legs, with a center strap to keep him from sliding off. My son is 37 inches tall. I am searching the adaptive equipment catalogs and have not found a chair yet. Does anyone have any suggestions?

MS, via the EP Web site

EDITOR'S NOTE:
The Adaptive Mall Web site (http://www.adaptivemall.com) features several different manufacturers of feeding chairs/booster seats that provide the kind of support you are looking for.

S

Responding to unkind remarks

My two daughters, ages 8 and 5, have multiple sulfatase deficiency (an extremely rare genetic disorder involving severe neurologic and skeletal abnormalities). My older daughter can no longer speak, but understands some words and tone of voice. She vocalizes by squealing. She does this quite often and sometimes loudly, especially in unfamiliar surroundings. Other people assume, since she looks "normal," that she is just misbehaving and I am "letting" her do it. She and I have suffered many rude comments by both patrons and staff, and have even been asked to leave some establishments. Her behavior is not one that I can change (I am grateful for any communication), so how should I respond in these situations? I am tired of feeling tongue-tied and humiliated, and I cannot keep her locked away.

CC, via the EP Web site

DR. FEUDTNER:
Perhaps having some business cards printed up for your daughters might help. The cards could have their names and their "job descriptions," which might include, "Living life to the fullest with multiple sulfatase deficiency." At the bottom of the card, you could have, "*For those of you who don't know, multiple sulfatase deficiency is an extremely rare genetic disorder involving severe neurological and skeletal abnormalities." Then, whenever someone says something unkind, you could say, "Oh, perhaps you want my daughter's business card. Somewhere down the line she might have a thing or two to teach us all." This would let you and your daughters have the final word.*

EDITOR'S NOTE: For more ideas, see "Satisfying the Curious" on page 48.

S

Depression in a child with cerebral palsy

I am looking for information regarding depression in children with cerebral palsy and seizures. My 10-year-old son has attempted suicide because he is angry about his condition. He has a mild mental impairment and has figured out that he is different from his peers. He is receiving counseling, but we were taken by surprise by this latest development. We have read nothing about this in books, but his doctors tell us that children with CP and seizures have a greater incidence (as much as five times higher) of suicide than the general population.

BY, via the EP Web site

DR. FEUDTNER:
Sadly, although still rare, suicide does appear to occur more frequently among people with epilepsy (just how much more frequently is debated). Futhermore, depression is common in everyone, including children with disabilities. We need to be constantly mindful of these possibilities, especially as children move into the teenage and young adult years.

S

Looking for a bike trailer

My 9-year-old daughter has scimitar syndrome (a congenital condition consisting of complex heart and lung anomalies). She cannot tolerate physical activity and functions developmentally at the level of a 4- to 5-year-old. We enjoy bicycling as a family and have used a baby-trailer type of carrier for her in the past, but she has gotten too big for it. We are looking for a trailer that can carry from 150-

continued on page 20

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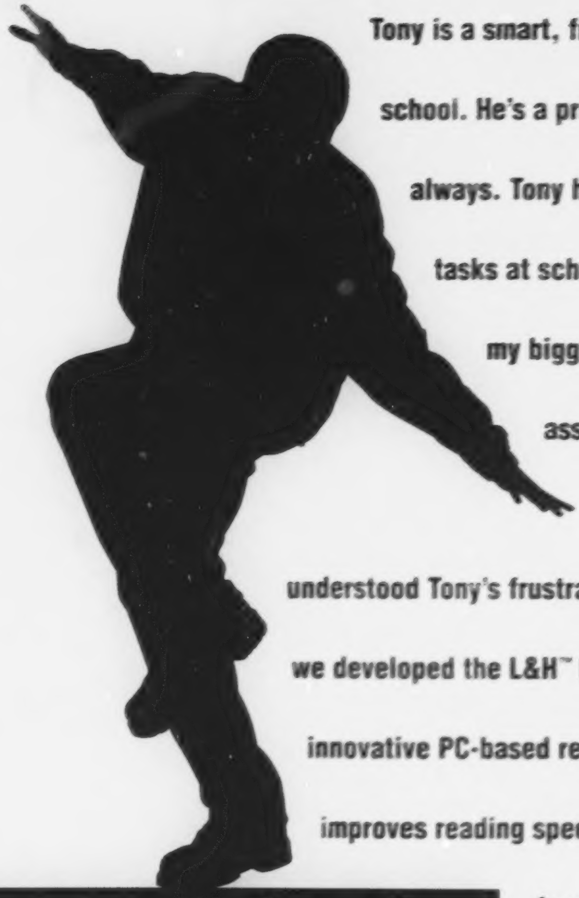

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Circle #39

continued from page 14

200 lbs. We are also on a budget and do not want something that will require a new bike. Does anyone know of such a product?

Elena, via the EP Web site

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Phone: (800) 669-1753

Respond

R Lip biting

PM (June 2000) has a 12-year-old daughter with cerebral palsy, high muscle tone, and a seizure disorder who bites her lips until they bleed. She does not seem able to release the bite, and there is no pattern to her behavior.

You might want to get your daughter's blood checked out. Ask the doctors to check her uric acid level. I have a son with Lesch-Nyhan syndrome (a rare metabolic disorder characterized by high levels of uric acid in the blood and severe neurologic disturbances, often including self-mutilation). He was diagnosed with cerebral palsy at age 1, and then with Lesch-Nyhan syndrome at 42 months. He started biting his bottom lip until it got infected, and after awhile we had to pull his teeth—he was destroying his bottom lip. Although Lesch-Nyhan syndrome is extremely rare in girls, you might want to ask her doctors about it.

GR, Pittsburgh, Pennsylvania

R Exercises for child with CP

ND (July 2000) has a 13-year-old daughter with spastic quadriplegic cerebral palsy. She is looking for exercises she can use to help relieve some of her daughter's spasticity. ND has carpal tunnel syndrome and it is difficult for her to maneuver her daughter.

I am a pediatric PT, and I applaud your efforts to help your daughter at home. Unfortunately, when considering exercises for an older child, you must also take into consideration your own safety (back injury and your carpal tunnel syndrome).

Depending on where you live, there are often programs such as aquatherapy and hippotherapy (horseback riding therapy) that can be fun as well as therapeutic. These programs may be costly, but no more so than traditional therapy. *(Editor's note: Your insurance may not cover alternative therapies. You may want to check with your provider.)* There are also several positioning devices for maintaining a prolonged stretch on the hamstrings, and soft splints for wrists and hands at night.

SG, via the EP Web site

Instant S&R

S Can my child receive Communion?

I am the mother of 6-year-old twins. My daughter is typically developing, but my son has severe mental retardation with a recurring seizure disorder. He cannot speak or communicate and is totally dependent. We are Catholic and I have been sending my daughter to catechism. There is no program for my son because he does not understand anything, let alone the concept of God. I am having trouble with the realization that my son will not be "allowed" to receive First Communion because, I am told, he does not understand. If there ever comes a time when he does understand, even if it is at age 25, only then can he receive communion. I am having a hard time accepting this, because both my children were baptized when neither one of them "understood" anything. I would like to know if anyone has had a similar situation.

Anonymous, via the EP Web site

R I have a daughter with autism who made her First Communion at age 11. She does not appear aware to most people, but I feel that all of our children have spirits that cannot be measured. We live in Seattle, and the Archdiocese has an office to help families who have members with disabilities. Maybe your diocese has such an office. I am sad that there is no place for my daughter in the religious education programs here, but my parish community has accepted my daughter and offered wonderful support.

Anne, via the EP Web site

EDITOR'S NOTE:
Try contacting the National Organization on Disability (N.O.D.) by phone at (202) 293-5960; E-mail: deese@nod.org; or visit their Web site at: http://www.nod.org.

You may also want to contact The National Catholic Office for Persons with Disabilities. Their phone number is (202) 529-2933; E-mail: ncpd@ncpd.org; Web site: http://www.ncpd.org.

S Concerns about drugs with no diagnosis

My son has emotional and behavior problems that often mimic ADHD (attention deficit-hyperactivity disorder) but without the hyperactivity. He has no problem with attention, and is bright, but very strong-minded. He has not been diagnosed and I am struggling through this with him, without drugs. Unfortunately, drugs seem to be the preferred method to control behavior. But since he is not a danger to himself or others, drugs seem to be only for my sake and that of his teachers.

Anonymous, via the EP Web site

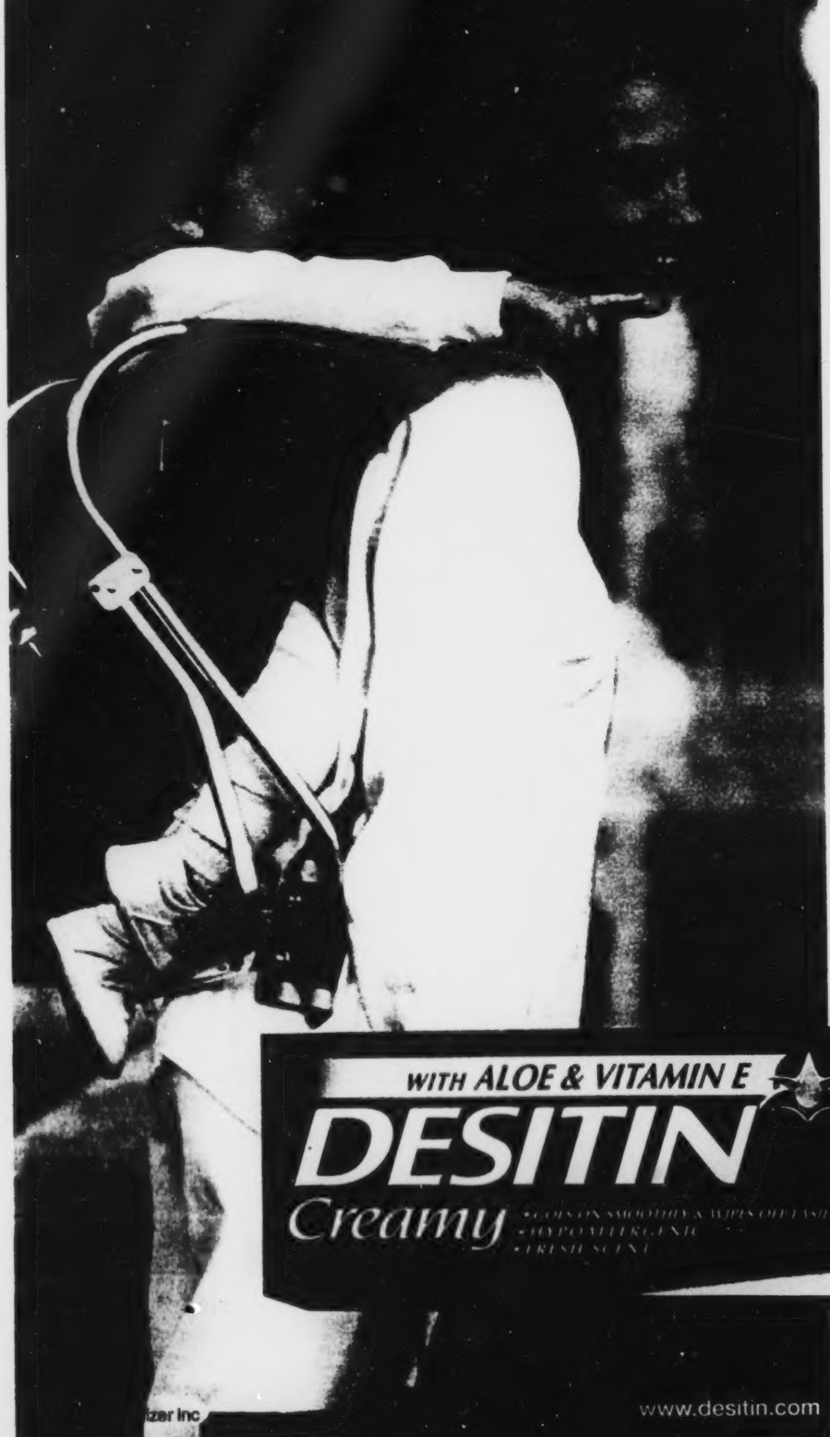
R My son was also diagnosed with ADHD, although he showed signs that were not typical. In the past two months, he has been diagnosed with sensory integration dysfunction (SID). I encourage anyone with a child who was diagnosed with ADHD to read up on SID also, in case their child is affected. My son is treated at home and at school with simple occupational therapies, and his response has been dramatic. We have been able to reduce the number of doses of Ritalin® he takes each day, and I am eager to see how he progresses.

GB, via the EP Web site

I just now returned from a parent/teacher CHADD (Children and Adults with Attention-Deficit/Hyperactivity Disorder) meeting where many items were discussed—among them the lack of many professionals to recognize and accurately diagnose these types of disorders. Check out the CHADD Web site: http://www.Chadd.org.

Anonymous, via the EP Web site

THE DESITIN CREAMY GENERATION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1357

Network offers free toy adaptations

The National Rehabilitation Awareness Foundation founded its Toy Adaptation Network for Children with Disabilities to help address the need for toy modification. The network served on EP's panel of experts for the October 2000 Annual Toy Issue. The network comprises 16 providers from around the country. All sites feature staff who are experts in serving children with disabilities, and modifications to toys are done for free. Modifications generally include adding Velcro® straps for better grasping; seat lift devices for elevation; dowels for better hand control; and enlargement of switches and controls to enable activation.

Services through the network can be accessed through the toll-free hotline, (888) FIX-A-TOY (349-2869). Callers will be directed to the site nearest their home. All sites have been selected based on familiarity and experience with children who have disabilities.

New government Web site

A new, free U.S. government Web site helps people get directly in touch with U.S. government services, as well as link with state and local governments. The new site, FirstGov.gov, allows users to instantly search more than 27 million U.S. government Web pages. This Web site can help individuals get information on finding a job, better healthcare, college loans, buying a home, and much more. Users can search FirstGov.gov in three different ways: by keyword, by topic, or by agency; or they can choose a topic from an extensive list. To find out more about this informative new site, go to http://www.firstgov.gov.

CALENDAR OF EVENTS

12/7-9 TASH

FOUNTAINEBLEAU HILTON RESORT AND TOWERS, MIAMI BEACH, FL

The conference will have over 2,200 advocates, educators, disability leaders, government officials, and university personnel, offering a networking opportunity. There will also be poster sessions, exhibits, and workshops.

For more information contact TASH at (410) 828-8274; Fax: (410) 828-6706; E-mail: tash@tash.org; Web site: http://www.tash.org.

2/4 **Special Camp Fair 2001**

AMERICAN RED CROSS

MANHATTAN, NEW YORK

The camp fair brings together representatives of day camps in New York City and sleep-away camps all over the Northeast that serve children with disabilities. This fair provides parents an opportunity to talk to camp representatives about their needs and how the camps can serve those needs.

For more information contact Resources for Children with Special Needs, Inc., at (212) 677-4650; Fax: (212) 254-4070; E-mail: info@resourcesnyc.org; Web site: http://www.resourcesnyc.org.

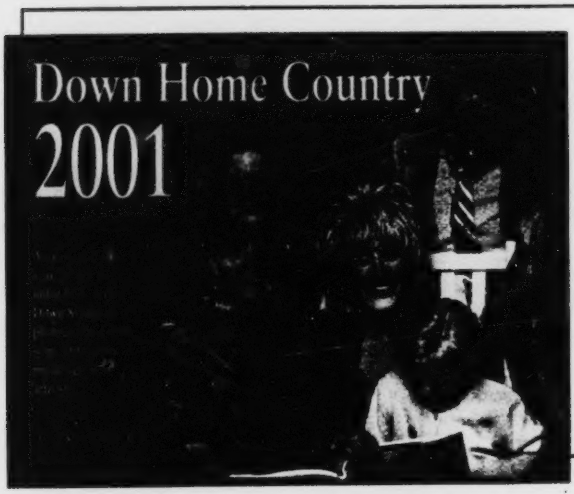
2/7-10 **Learning Disabilities Association of America (LDA) International Conference**

38TH ANNUAL CONFERENCE ON LEARNING DISABILITIES

Hilton Hotel, New York, NY

Topics will include sessions on assessment, early childhood, technology, and transition.

For more information contact LDA at (888) 300-6710 or (412) 341-1515; Fax: (412) 344-0224; E-mail: ldsnatl@usaor.net; or Web site: http://www.ldaamerica.org.



Down Home Country® 2001 Calendar

The Down Syndrome Association of Middle Tennessee's (DSAMT) Down Home Country® 2001 Calendar is now available for purchase. The DSAMT has produced and published this calendar to help create public awareness and acceptance of individuals with Down syndrome. The organization hopes to raise money to provide programs for families in Middle Tennessee.

The calendars feature some of country music's top stars, such as Dolly Parton, Naomi Judd, and Patty Loveless, photographed with individuals with Down syndrome. The full color glossy calendars are $15.00 each. Allow 2-3 weeks for delivery. For more information contact the DSAMT at (615) 386-9002; E-mail: dsamt@bellsouth.net; or Web site: http://www.dsamt.org.

continued on page 24

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continued from page 22

Online information from the Disabilities Rights Office

The Disabilities Rights Office (DRO) is a new office within the Consumer Information Bureau at the Federal Communications Commission (FCC). The FCC enforces laws that make sure that people with disabilities have access to electronic communications. For more information or to subscribe to receive free information about FCC activities from the DRO mailing list, go to http://www.fcc.gov/cib/dro.

New Jersey sled hockey team

The New Jersey Devils Youth Hockey Club is starting a sled hockey league. Sled hockey, a sport very similar to "stand up" hockey, allows children and adult participants who have physical disabilities the opportunity to experience the sport of ice hockey. The sled is a metal tubular device with ice blades under the seat and a small support device at the front. The participant sits 4 ins. above the ice on the sled with the center of gravity balanced over the skate blades. The two custom made sticks are held in each hand. Metallic "picks" on one end which are necessary for propulsion provide the grip in the ice. Anyone in the Northern New Jersey area who is interested in participating in this league should call the New Jersey Devils Youth Hockey Club(973) 731-7177; (973) 731-8577; or call Merrill Levine at (201) 599-1676.

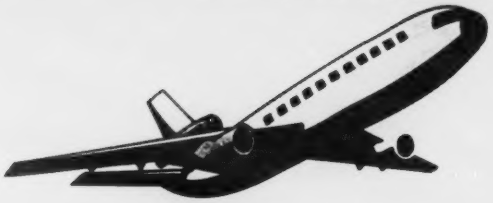
Free brochure for adapting motor vehicles

A free brochure entitled "Adapting Motor Vehicles for People with Disabilities" is available online. The information in this brochure is based on the experiences of driver rehabilitation specialists and other professionals who work with individuals who require adaptive devices for their motor vehicles. To access the brochure go to http://www.nhtsa.dot.gov/cars/rules/adaptive/brochure/brochure.html.

Tell us about: Daycare for children with special needs

For our February issue, we would like to include parent experiences—successful or otherwise—with finding daycare for their child with special needs. We would also like to hear from daycare providers who have cared for children with special needs.

Please share your stories with us by December 20, 2000. Be sure to include your name, contact information including daytime phone number. Submissions can be e-mailed to epedit@aol.com or sent via regular mail to Exceptional Parent 555 Kinderkamack Rd., Oradell, NJ 07649-1517



DOT seeks input on airline service to passengers with disabilities

The U.S. Department of Transportation's (DOT) Office of Inspector General (OIG) is seeking public comments on how airlines are accommodating the needs of air travelers with disabilities and special needs. The OIG will use this information as part of its report to Congress due December 31, 2000. To complete the form online, go to http://www.oig.dot.gov and click on "Airline Customer Service." To obtain a hard copy, call (800) 884-9190.

Folio:
EDITORIAL EXCELLENCE

EP honored with Editorial Excellence award

Exceptional Parent received a Gold Award from Folio: Magazine, the preeminent chronicler of the publishing industry. The Sepetmeber 1999 issue was selected for the award for Editorial Excellence. The Folio: Editorial award recognizes magazines which best exemplify their editorial mission in their content, as well as over all presentation and design. One of the judges had this to say about EP, "Exceptional Parent's mission statement is rock-solid and crystal clear and has been that way throughout this magazine's nearly 30 year existence. It succeeds in doing what every magazine wants to do: build a true community among its readers by getting to know who they are and delivering what they really want and need to know."

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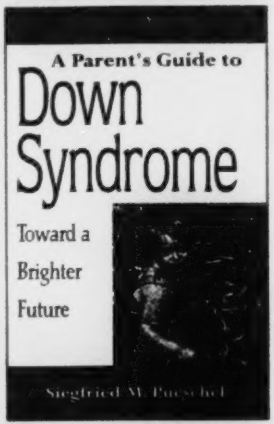

A Parent's Guide to Down Syndrome: Toward a Brighter Future

BY SIEGFRIED M. PUESCHEL, MD, PHD, JD, MPH
PAUL H. BROOKES PUBLISHING CO. 2000
AVAILABLE FROM THE EP LIBRARY (800) 535-1910
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book notes

A PARENT'S GUIDE TO DOWN SYNDROME opens with an introduction by Claire D. Canning, parent of an adult daughter with Down syndrome. In this introduction, entitled "From Parent to Parent," Canning writes, "What do we as parents wish for our children's futures? I think the most valuable thing we can give is complete acceptance of them just as they are and a desire to make them as happy, caring, and independent as possible. From the community, we ask for compassion—not pity—and the chance for them to prove themselves as fully as possible while being accorded the rights of a human being within their capabilities."

This newly revised and updated edition comprises the latest methods in treatments and therapies, with an understanding look at how parents can give broad-based guidance to all aspects of the life of a child with Down syndrome from before birth to adulthood. In 23 chapters, Dr. Siegfried M. Pueschel, MD, PhD, JD, MPH, and various authors (all of whom are parents of children with Down syndrome or have extensive experience in working with children with Down Syndrome) cover many different topics, including the causes of Down syndrome; medical concerns; treatments and therapies; gross motor development; fine motor skills and play; education from childhood through adolescence; and working in the community. At the end of each chapter is a list of references and suggested reading.

Chapter 9, "What to Expect As Your Child Develops," by Claire Canning and Dr. Pueschel, explodes the stereotypes associated with Down syndrome. The chapter notes that most published material reporting that individuals with Down syndrome all have severe mental retardation coupled with certain physical attributes comes

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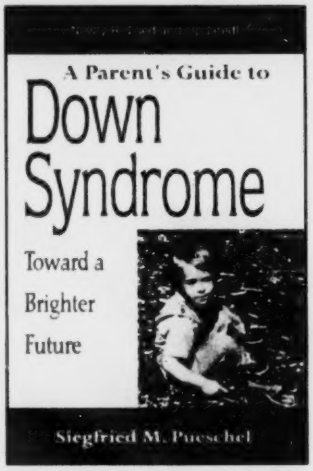
PROVEN ANSWERS FOR PARENTS
OF CHILDREN WITH DOWN SYNDROME

PRAISE FOR THE FIRST EDITION:

"This book is an 'absolute must' not only for new parents but for all parents."

—MARIAN AND FRANK BURKE, PARENTS OF CHRIS BURKE, STAR OF *LIFE GOES ON*



A Parent's Guide to Down Syndrome—the book that thousands of new parents and professionals turn to as their first source of information on Down syndrome—is newly revised and updated! The second edition, written by Dr. Pueschel and group of expert parents, doctors, and educators, covers everything you need to know about raising your child with Down syndrome.

In this terrific guide, Dr. Pueschel combines the best of both worlds of knowledge as both a physician and a parent of a Down syndrome child. With wit, intelligence, candor, and charm, Dr. Pueschel speaks to you about what matters most—enabling you to help your son or daughter enjoy all the opportunities that life brings.

STOCK NUMBER: 4528 • PRICE: $21.95 • 2001 • 352 PAGES • 5½ X 8¼ • PAPERBACK • ISBN 1-55766-452-8

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Circle #23

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from data about individuals living in institutions. The writers counter by highlighting the uniqueness of the individual and provide an overview based on "studies of children raised in the loving, accepting, and protective atmosphere of the home, which better allows children to reach their full potential."

Following is an excerpt from this chapter:

"As in other areas of development, the intellectual abilities of the child with Down syndrome often have been underestimated in the past, and there is a wide range of cognitive abilities in children with Down syndrome. Recent reports as well as the author's own investigations negate the previous assumptions that indicate that children with Down syndrome usually have severe or profound mental retardation. Contemporary studies have found that the majority of children with Down syndrome have mild to moderate mental retardation....Some children function intellectually in the borderline or low-average range, and only a few children have severe mental retardation.

"Another misconception is that the mental ability of older individuals with Down syndrome declines. This has not been observed in a group of children with Down syndrome whom we have studied for several years.

"Further research conducted in the 1990s indicated that cognitive development can continue during adolescence and adulthood, although sometimes at a slower rate than during the childhood years. Thus, the assertion that there is a plateauing of mental abilities is a myth.

"In addition, the IQ of individuals with Down syndrome does not provide all the information about their overall function. Social abilities, adaptive behavior, independent living skills, employability, and recreation may correlate poorly with cognitive abilities. Intellectual functioning may play only a limited role in how a person with Down syndrome performs academically, socially, and in day-to-day life. On the basis of this new information, the future for the person with Down syndrome should certainly be more optimistic today than ever before."

The final chapter, "Does Parenting Ever End?" by Dorothy Robison, Marty Wyngaarden Krauss, and Marsha Mailick Seltzer, addresses the questions: "What will life be like for my child when he or she is grown?"; "Will it be possible for my child to live independently or semi-independently?"; "How will I, as a parent, make the best decisions regarding how to support my child as an adult?"; and, "What will my life be like?" The chapter is an analysis of the findings from a 10-year study funded by the National Institute on Aging. It covers the different living options chosen by young adults with Down syndrome, and the reasons behind their particular choice. Residences, living at home, and living independently are all discussed.

Excerpted with permission from the publisher.

Annandale Village: *Their Community... With Our Help!*

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...to perpetuate a private, nonprofit Village community offering adults with developmental disabilities an improved quality of life. The Village provides professionally managed and cost effective lifestyle alternatives through specialized programs and services flexible enough to meet individual needs. These programs are a significant part of our original goal of offering a balance of freedom, encouragement and instruction that help each Villager achieve his or her own level of independence and fulfillment.

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- Creative and Performing Arts
- Recreational and LeisureActivities with Skills Training for Special Olympics
- Daily Living / Life Skills

Photo courtesy of Eagle's Cry Productions

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Circle #20

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Circle #22

ADOPTION

The family is the first community to welcome a child. Parents, siblings, grandparents, and extended family and friends provide the nurturing needed to survive and thrive, and eventually prepare and help the child to access the community beyond the shelter of home. For some children with disabilities, adoption is often the only hope they have for a family. In this special section of articles, we include profiles of families who have welcomed children who might otherwise spend their lives in institutions, as well as organizations that support and enable adoption. We also take a look at the issue of custody relinquishment—the heartbreaking dilemma that has faced some parents of children with mental health needs.

—The Editors

Angels Among Us

by Kerry Pianoforte

Some people are thrust into the role of exceptional parent, others choose it. Regardless of how it happens, being an exceptional parent always requires an abundance of love, patience, and caring. Several of these exceptional-by-choice parents were among the 120 families from every state across the nation who were recently recognized as "Angels in Adoption" by the Congressional Coalition on Adoption. These "Angels" have made a difference in the lives of children, some of whom have special needs, through adoption or foster care. A nonpartisan alliance of Members of Congress who are dedicated to improving adoption policy and practice in the US, the Coalition seeks to raise awareness both in Congress and among the general public about the positive aspects of adoption. The Coalition also serves as a resource to its members as they write legislation to improve adoption policy and practice. Senator John D. Rockefeller, IV (D-WV), a member of the Coalition, explains, "It is vital to build public awareness about adoption. There are over 100,000 children in our foster care system waiting for adoption. Finding caring families for these children should be a priority. As one of the leaders in crafting the 1997 Adoption and Safe Families Act, I strongly believe that every child deserves a safe, stable, and permanent home."

In presenting the award, Senator Rockefeller noted, "It takes a special family to open their hearts and homes to our Nation's children. Families considering adoption should ask lots of questions so that they are fully prepared for adoption. It can be challenging, but it is important and rewarding." Many of the "Angels" have gone above and beyond and adopted children who are often hard to place, such as children considered high risk, children with special needs, and sibling groups. Two of these extraordinary "Angel" honorees, the Merrymans and the Washburns, share their story with EP.

"Angel" awardees, the Merrymans (rear l.-r.: Scott, Faith, Hope; front l-r: Charity Megan and Richard), pose with Sen. Rockefeller (r.) and Steve Wiseman (far r.), director of the W. Virginia Developmental Disabilities Council, who nominated the family for the award.

THE MERRYMAN FAMILY: NO TIME TO WASTE

After raising their three biological children, Scott and Faith Merryman of West Virginia decided to adopt. Though they had not planned on adopting a child with special needs, the couple had a lot of love to give and did not want to be placed on a waiting list for a typically developing child. They started with 5-year-old Richard, now 26, who has cerebral palsy. Hope, 19, came next and was considered a high-risk child. She was adopted at 13 days old because her birth parents were unable to take care of her. Charity Megan was brought into the family from an institution when she was 14 months old as a foster child. Charity is now 17, and has severe disabilities as a result of amniotic bands. She attends school in a self-contained special education classroom. The

1364

The Dave Thomas Foundation for Adoption

EP had the opportunity to speak with Dave Thomas, founder of the fast-food franchise, Wendy's. Mr. Thomas also heads The Dave Thomas Foundation for Adoption. The Foundation, which was honored last year by the Congressional Coalition on Adoption, is dedicated to raising public awareness on adoption, educating prospective parents on the adoption process, and forming public and private partnerships to help make the process easier and more affordable.

Dave Thomas, founder of Wendy's, with some of the children served by his foundation for adoption.

Q *Parenting a child with special needs can be very challenging. What does your Foundation offer as supports for adoptive parents?*

A The Dave Thomas Foundation for Adoption (DTFA) funds a variety of programs and grants that specifically help adoptive parents. They include: http://www.adoptnet.org (a Web site specifically designed for adoptive parents), http://www.adopt.org (a photolisting of thousands of waiting children from the U.S. and NAATRIN (a program that offers adoption subsidy information for parents). For more information on these programs, visit the North American Council on Adoptable Children at http://www.nacac.org.

Q *You were adopted. Can you give some examples of the things your adoptive parents did for you?*

A I would have to say that my Grandmother Minnie Sinclair has had the greatest influence on my life. She taught me important lessons that I still follow to this day. Most importantly, she taught me that every person has value and something to offer. She also taught me to believe in myself and to follow my dreams. That was probably her greatest gift to me.

Q *Do you have any advice for prospective adoptive parents of children with and without special needs?*

A Consider adoption; it works for everyone—the parents and the children. There are about 122,000 waiting children in the US and they all deserve a permanent home and a loving family. These children aren't someone else's responsibility—they're our responsibility. These children need to be adopted so they can enjoy their childhood, rather than wondering if they'll ever be part of a forever family. If you have it in your heart to adopt and open your home to a waiting child, your life will be enriched in ways you never dreamed.

Inspired to adopt

Dawn Voss, a Wendy's division vice president, was inspired to adopt children as a result of her involvement with Dave Thomas and his Foundation. According to Dawn, "Through the work of The Dave Thomas Foundation, I attend a lot of events and see a lot of kids. It seems to me what they need is some love and attention." Hearing stories about other families in her company magazine inspired Dawn and her husband, Rick Scott, to look into adopting a child. Dawn and Rick adopted two children—Cheyenne, 3, and Calvin, 5. Dawn explains, "We had originally thought of one child. We met Calvin, who was in a shelter, and we decided we wanted to adopt him. As we pursued the adoption, we found out that his sister had been placed separately. We felt that they needed to be together after talking to him about it."

Dawn explains that while raising children who have special needs is challenging, she and her husband have learned some important life lessons. "For one thing, you feel the pain they've gone through. It's hard to know when or where it's going to come out, so you have to have some patience to help them with that. It's easy to see all the work we have to do, but it's taught me to focus on the positive things. They're just wonderful kids. They've worked so hard at trying to better themselves, and I think that is very inspirational considering what they have been through."

family is currently in the process of adopting her.

According to Scott, "Adopting children with special needs has changed our goals and objectives." Because of the experience they have with children with special needs, both parents now work in the disability field. Scott, a former truck driver and dock worker, currently works as a mentor and aid for individuals with autism. Faith works for parent information services. Faith says that her children have given her a new perspective on life. "These kids make you stop and smell the flowers."

The Merrymans believe that children need to gain as much independence as possible and have provided a strong home environment to encourage that. Richard now lives on his own in his own apartment. He is a member of the West Virginia Team of the President's Committee on Mental and Retardation and the West Virginia Developmental Disabilities Council as well as a self-directed activist on accessibility and other disability issues. Hope works as an assistant manager at a local restaurant and studies sign language. Faith says their youngest daughter Charity Megan, "is here for a reason. And with her smile, she has touched so many people's lives. We don't have a clue as to how many people have been moved just by being around her."

A FAMILY ON THE GO: THE WASHBURNS

While raising two children, Jackie Washburn tried to go back to work outside of her home, but she found herself longing to be back there with her children. Jackie wanted to work at home and "do something

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Adopting a Dream

The Badeau Family at home: Sue and Hector surrounded by their kids.

Ever since age 10, when she read a book about a family of adopted children, Susan Badeau wanted a family "like that." Her motivation to achieve that goal was enhanced by her real-life experience working with special needs children while in college, and being able to share her dream with her husband Hector. The couple have dedicated their lives to helping children in need. Together, the Badeaus have 20 children by adoption and two by birth. They have also served as foster parents and worked with youth and adults with developmental and mental health disabilities. Sue credits her children for teaching her "enough to fill about 10 books!" From appreciating the progress, however small, that each of her children makes to learning how to grieve from the loss of one child, Sue has used her experiences to help her own family and on behalf of other children and families with special needs. "I have learned to be a fighter and an advocate," she says. Among her extensive efforts, Sue she was also involved in developing the first "Angels in Adoption" Award Program. Through her work with the National Adoption Center, she authored "The Adoption Roadmap," a guide for adoptive parent preparation. (The guide can be found on the Center's Web site: http://www.adopt-net.org.) Sue explains, "Our children are our teachers. I have learned to truly live one day at a time. I have learned the importance of connections between people, multiple ways of communicating (some of my children are deaf, non-verbal, etc.). I have learned what really matters in life and that being loved has nothing to do with being "lovable" in the world's eyes." (Editor's Note: Sue has written on another side of parenting, "No Good Choice: Avoiding Custody Relinquishment," which appears this month on page 42.)

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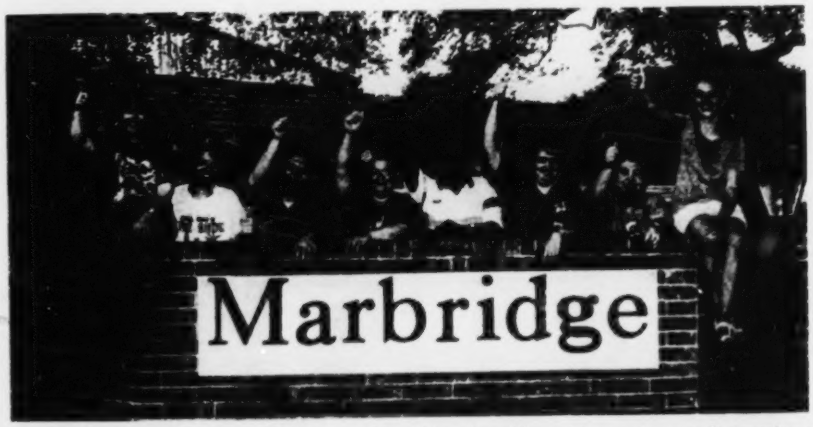
"A Whole New Life"



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Circle #43

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Kids just want to have

Let's have fun.

Otto Bock

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that would give me a feeling of accomplishment and give back to the community." That's when Jackie and her husband, Tom, began fostering children. Although the Washburns did not request children with special needs, they were asked to take in a little boy who had meningitis because of Jackie's background in special education. Jackie recalls, "We had him for five years, he passed away. We did such a good job that we got the reputation that we would take hard-to-place kids." Jackie remembers when they adopted their first child, Heather, "We had not even thought about adoption. But then when I thought about the fact that I might never see her again, it was a really strange bond that I felt." The family continued to foster through the next 17 years, in all taking in about 70 children and Jackie says, "as the kids that were our foster children would become available for adoption, we just kept them. So unless they went home they stayed with us".

The Washburn clan enjoy the outdoors while on a road trip.

The family now numbers 12 children (8 still living at home). Most of the children have special needs. Some of the children's medical needs can be quite demanding. Jackie has the in-home help of a certified nurse's assistant six hours a day and a nurse 12 hours a day to help with her son Matthew, who is g-tube fed and has a tracheostomy. Jackie notices that children are a family in every sense of the word, interacting and caring for one another. "I have a great group of kids. They work well together. You should see our daughter Missy. She is great with Matthew. As soon as she walks into the house, she goes right over to him and has to check on him." Despite the daily demands of raising a special family, they are firm optimists. The family, who makes their home in Colorado is active in year-round sports and loves to travel. Last summer they embarked on a six-week camping trip to the West in their RV, and next year they hope to spend the summer touring the North. Says Jackie, "I enjoy my family. I think it's a lot of fun and my kids are really non-judgmental." ■

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Circle #26

ADOPTION

Barbara and Pat Canale always wanted a family of their own, and for them, adoption was the only way. In 1991 they adopted Juliana, now 9, and in 1993 they added Andrea, now 8, to their family. Both girls were adopted from orphanages in Romania and both have physical and developmental delays.

Barbara Canale remembers the conditions in both orphanages as "deplorable," and led her to suspect that that may be related to her daughters' disabilities. Since their adoption, however, the girls have made considerable progress, and the Canales feel fortunate and blessed in having been given two "incredibly wonderful children."

Today, Andrea and Juliana are "highly functional," and both are in regular classrooms. Barbara recalls some of the struggles she and her husband had to endure to ensure their daughters' progress: "When my children were younger," she explains, "we traveled out of state to get evaluations by professionals who dealt with children in institutions, and who had experience with the specific issues my girls were struggling with. We attended conferences across the country to educate ourselves and understand the programs our children were enrolled in. We weren't afraid to roll up our sleeves and delve into a world unknown to a lot of parents—a world of doctors, hospitals, therapists, evaluations, and IEPs."

For parents who have already adopted internationally, and perceive that there may be a problem with their child, Barbara and Pat Canale recommend they rely on their instincts: "The best advice is that parents trust their gut. If they feel there is a problem, there probably is. They should consult with specialists who understand the uniqueness of children who are institutionalized in adoption clinics." For those thinking about adopting a child with special needs, the Canales advise being prepared for many ups and downs. "Potential parents need to be aware that problems exist; not all them are easy to deal with, and some may never be resolved. Parenting a child with special needs and medical disabilities is gut-wrenching and perhaps the hardest job I've ever done. However, I wouldn't trade the experience for anything in the world. Raising my children has made me a stronger, more compassionate person."

Barbara shared her story with EP about how her daughter, Andrea, taught her the importance of having dreams and fulfilling them.

A Place Where Dreams Are Made

by Barbara Canale

Barbara Canale with her two daughters, Juliana, 9 (left) and Andrea.

When my daughter Andrea asked me if she could go to gymnastics class, I gave her my typical response: "We'll see."

I say "we'll see" because I am asked so many questions by my two children that I can't possibly sit down and rationalize each and every request. I usually wait until they have made the same request ten billion times before I will consider it. After they have met that criteria, I play the devil's advocate by describing how difficult it will be for them to do whatever it is they want to do.

In the case of gymnastics lessons, I explain to Andrea that every Monday she cannot play with friends, watch videos, or anything else she wants to do. Basically, I am trying to talk her out of gymnastics in favor of playing on the swing set in our backyard. She begs me every waking moment to participate in a program that is located 25 miles away. Andrea found this place.

There are gymnastics lessons in our town, but they cater to children who are exceptionally gifted in coordination. Andrea, on the other hand, can barely walk a straight line on the sidewalk without wobbling or falling down. They also specialize in priming children for stiff competition. Andrea can't tie her shoes or wipe her nose, and she could care less about competition. I went to this fancy center and saw the girls perform. Their dreams of winning gold for their team and country were evident. Andrea has a few fantasy dreams of her own. Winning gold is not one of them. Her biggest dream is just to get her foot inside the gym door.

The center that Andrea found is a place where little girls' dreams are fostered on a floor covered with red, white, and blue mats. Inside, coaches liberally dish out positive reinforcement. Self-esteem is at a premium inside this gym. I can see the years invested in physical and occupational therapy are paying off for my little girl. Andrea's timid body scurries out to join a group of girls tumbling systematically. For the first time in Andrea's life, there is a reason and a purpose to her tumbling, spinning, and crashing.

I knew that Andrea was hooked, like a wide mouth bass at a fishing derby, after her first trial visit. She smiled all of the time. Finally, Andrea

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[redacted]

Juliana (left) and Andrea were adopted from Romanian orphanages.

was passionate about something. No matter how much the lessons cost, we would make the sacrifice in order to allow her the chance to make a go of this. Sports can be great for children if they are taught in a positive manner. The 50-mile trip was worth my time and every ounce of gas my car used to get us there and back. I had found a gym that cared about its kids more than gold medals. I found a place where dreams are made.

In the middle of January, when temperatures were dipping into the single digits, Andrea was never too cold to venture out. She was never too tired or hungry because she never lost the spirit. I was the one always grumbling about something—never Andrea. Once I was there, however, Andrea's love of tumbling transformed me with a fire of warmth. She was the master of her domain at that center. Perseverance and therapy has enabled Andrea to perform as well as she does. Even though I walked into Monday night class with a newspaper tucked under my arm, I never read a word. My eyes were always glued to Andrea. I was in awe watching her. She always fell asleep on the one hour car tip home. She was exhausted from a full day of school and a rough workout at the gym. She was only 5 years old and was pushing herself harder than I would ever push a child her age. She was my inspiration to push myself to the limits when I felt tested by life. Imagine that—a child inspiring me.

As class was winding down for the summer, Andrea began complaining of pain in her foot. For Andrea to complain of pain, I knew it must be bad. Right before her end-of-the-year performance, which she had worked on for months, a rare tumor was found in her foot. Andrea was determined to be in the show. Reluctantly, I let her go. At the end, her coaches called her to stand on a platform to be presented with a gold medal, just like in the real Olympics, and she accepted it with the same amount of pride. On that day I discovered the place in my heart where pain once festered was now replaced with a sense of hope. I had no idea that inside my heart there was also a place where dreams are made. Andrea was the one to find that place, too. ■

The Canale family lives in New York.

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GRANDPARENT ADOPTION:

The Clark Family

by Marge Clark

Levi and his sister, Tia, get a ride from Dad, Dave. The children have exceeded the expectations of many professionals and their parents continue to advocate for them.

My husband Dave and I adopted our grandchildren, Levi and Tia, when they were infants. Both children have cerebral palsy. Their mother could no longer care for them, and we decided we couldn't turn them away. They needed us.

By the time we decided to adopt Levi, the bond that had grown between us was very special. We knew we had to become his parents. We also noticed that he wasn't progressing physically as he should have been. But we never let that influence our decision to become his Mom and Dad.

With Tia, who came later, we were equally sure that she needed to be with us and her half-brother Levi. At first it took some getting used to. It wasn't until six months after we met her that she gave us eye contact—much later for people whom she did not know. All she could do was turn from her stomach to her back. She couldn't sit up, and she couldn't even suck from a nipple. I had to use preemie nipples and move them back and forth in her mouth to make the milk come. Since then, we have never looked back.

Though neither child can talk, both Levi, now 11, and Tia, 10, are learning to use communication devices. They

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can also walk with the aid of a walker. Both children have seizures as well, which are controlled by medication, but that does not stop them from riding their own bikes independently and riding their horse, Rocky, while their Dad leads them. We do not let negative words like "can't" or "never" be used when it has to do with Levi and Tia. They will prove those words wrong almost every time.

In school, aside from Levi's sixth grade home economics class, neither child is currently taking regular education classes. The fight to keep Levi even in his one regular-ed class has been difficult. I want him to mix with the other kids. Everybody likes him, and I don't want him segregated.

During his IEP meetings I have been told quite often that Levi does not have the cognitive abilities to learn things like printing his name or other academic skills. I will not stand for this, however, because I know better. Recently, a children's respite provider and I worked with Levi. By the time he went back to school in the fall, he could print his name, and has since made great progress in all areas. He has advanced past many goals which we were told he would never accomplish. In fact, both Tia and Levi are doing many things that the professionals told us they would never be able to do. So I continue to be vocal and fight for them. My husband stays home with the kids while I go out and do the advocating.

I have been told many times that I have unrealistic expectations—that I am in denial. Some even wonder if being a grandparent—not a parent—is an obstacle in advocating and caring for Levi and Tia. But my answer to that is, we adopted Levi and Tia as our own. In our minds, that is enough to make us the parents. They're just our kids, and we see no difference.

Physically there are some challenges to being older than regular parents. Lifting them was difficult, but now they can help me get them on their feet or in and out of the tub. We also have an adapted van, so transporting them is easy.

I know that my children have to be exposed to different things in order to learn. It's the educators who need to move beyond the disabilities and broaden their expectations of these children. Special children have to try so much harder to reach a goal, but they really have more ambition than most people give them credit for. Each one is unique and will learn at different rates, just like regular-ed children learn.

While my husband and I do not expect Levi or Tia to become the President of the United States, we do have great expectations for them. This helps us to work them harder, and we become extremely happy with every bit of progress they make. We know that there will be more to come.

We all know how much more work it is to take care of our special children. The hardest, most heartbreaking thing is how hard we have to fight for every bit of equal rights for them. But we should never give up and never let anyone else give up on them either. The greatest reward in the world is when they accomplish something. It's like the sun just came out. Everything's worth it. ■

The Clark family makes their home in Wyoming.

I wonder how Webster defines adoption? I am tempted to search for its definition, but would I truly find its meaning in a book of words written by someone who, perhaps, has no idea what this heavenly word means to a child or a family? I choose not to waste my time, but to search in my heart instead.

ADOPTION

Helping young lives take wing

by Carmen Parladorio*

I am a single parent of two adopted girls who are now 6 years old. One of them, Elyse*, has speech and developmental delays. My other daughter, Angelica*, does not have a disability, but she does have some behavioral problems. The girls come from completely different backgrounds.

Even though I am not genetically responsible for the brown or blue eyes, the brown or blonde hair, their wellness or disabilities, I am accountable for their mental and physical wellness and often can't help but feel responsible for any lack of these. In my heart they are my daughters, and this is one of the ways I display that my heart and mind know these children as mine.

When I began my parenting experience as a foster parent, I was not sure if I could endure the rigors and responsibility of caring for a child. Being a single parent of two children, one of whom has special needs, is not an easy road to travel. But once I dug in, I knew I could do it. In fact, if I could do it for a hundred more kids, I would. There are so many unwanted children waiting for a home, and we, as parents, whether biological or not, have so much to contribute to them. And the most rewarding and fulfilling thing is: they love you back!

Learning to fly

While watching the movie Dumbo recently with my daughters, I thought of how much the story is like that of many children, and, of course, my own. Because Jumbo Jr. had big ears, and, therefore, was different than the other elephants, he was rejected. Even his mother was chained, locked, labeled, and called "mad" when she tried to defend her son. Such arrogance! What gave the other elephants the right to expel them from their kind?

Elyse and Angelica have been through their share of growing pains, like all kids, but on the whole, they both do very well in school. Elyse attends a special education program in a small classroom with individualized attention. I meet with the teachers regularly, and they say that although she's a slow learner, she's progressing well. She's just about your typical kindergartener, they say. The teachers and therapists who work with her are very accommodating to her needs, and they even include me in making decisions regarding her education and care. Her sister Angelica is also performing well, too.

My experience with my daughters has shown me that special kids can do a lot of things if people just let them be, and stop laughing at them or making fun of them. If you encourage and nourish their dreams and desires, they can do anything. Elyse has come a long way, and I'm impressed at what she is able to do. The one thing she is unable to do seems so small compared to everything she has accomplished.

It took a tiny mouse to help Jumbo, Jr. win back his self confidence. Because of his unique abilities, which were unknown to all, the brave little elephant learned to fly. I know if my daughter Elyse could speak well, she would "fly," too. ■

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*NAMES HAVE BEEN CHANGED AT THE AUTHOR'S REQUEST.

The Nowakoskis. Back row (l-r): Jensen, Lacey Hittle, Dawn, Jeremy, and John. Front row (l-r): Keyen, Jonni, Pashi, Arian, and Addi.

ADOPTION

Talk About the Brady Bunch

by David Chamalian

When Dawn and John Nowakoski got together, they, too, "knew it was much more than a hunch" that a big family was in their future. Lacey, 12, Dawn's daughter from a previous marriage (and author of this month's *Children's Page*), is the eldest of the group. Following her are four of Dawn's and John's biological children: Jensen, 9, Arian, 8, Jonni, 6, and Keyen, 4. And rounding out the bunch, the Nowakoskis decided to foster-parent, then adopt, three other children: Addi, 8, Pashi, 4, and finally, Jeremy, 2, who has special needs.

The first thing that may come to mind in this case is: Where do people get the strength to care for so many children? For Dawn and John, it has been more a matter of desire than strength. "When you are doing something you've always wanted to do, you don't think about how hard it is...you just do it. We feel privileged to be raising a house full of children I have no doubt are going to make their own personal mark on this world." It is not often until late evening, however, that the couple can ponder the enormity of their task and responsibility. "There are times we fall into bed at night and wonder how we got through a difficult day."

Jeremy, the last child the Nowakoskis adopted, has Ohdo blepharophimosis (OB), a rare genetic disorder that is associated with learning disabilities, congenital heart disease, small eye openings, drooping eyelids, and small teeth. (Jeremy does not have congenital heart disease, but has a hearing impairment and is nonverbal.) However, says Dawn, despite these challenges, Jeremy was the ideal final touch to her ideal family, fitting right in with everyone else. "After we'd been foster parents for a few years," Dawn relates, "we decided we wanted to adopt one more child, a child with special needs. So, we did a lot of the legwork ourselves, getting our names out there and searching for a child." A phone call at "just the right time" then forged the connection between the Nowakoskis and Jeremy. "Jeremy's birth parents had decided to make an adoption plan for him, but still wanted to be a part of his life. We were very open to that, and after we met, we knew our families were a perfect match. Jeremy was the child we had been looking for." Now, both his adoptive family and birth family, which includes biological siblings, share a unique bond. "He couldn't be more loved!" exclaims Dawn.

Though there can be some element of discrimination against large families who seek adoption, notes Dawn, the placement of Jeremy was made easier because the adoption agents viewed the Nowakoskis as an experienced, functional, adoptive family. Before making the final decision to adopt, however, Dawn and John had to get input from their most important of sources: their children. "Communication is the most important element of any family, but especially when you have a diverse family such as ours. We've always discussed our adoption plans with our children, not to let them help decide, but to listen to their opinions and concerns regarding our decisions–watch for any red flags."

What do the children think about this group "that somehow formed a family"? "Our children were young when we began foster parenting, so they don't think our family is anything out of the ordinary. I think they feel special to be a part of it." ■

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Circle #35

FINDING THE WAY HOME

Adopt A Special Kid places children with loving parents

Adopt a Special Kid—history and services

Adopt A Special Kid (AASK) was founded 27 years ago by Dorothy and Bob DeBolt, who are parents of 14 adopted children with disabilities as well as six birth children. Since its grassroots beginning in the DeBolt's garage, AASK has placed thousands of children with special needs, including children with a range of disabilities: from mild cerebral palsy to fetal alcohol syndrome (FAS) to conditions requiring extensive medical intervention. AASK also places many children who have issues not so clearly classified as disabilities: emotional/behavioral disorders, drug and alcohol exposure, a history of many foster placements, or brothers and sisters who need to be adopted together.

Throughout its history, AASK has been dedi-

Linda's Story

Linda Hargreaves discovered AASK 10 years ago. Since then, Linda and AASK have forged a great partnership. In providing a permanent adoptive home for some of the hardest-to-place waiting children, Linda's story is just one of many that illustrates how successfully families can adopt children with disabilities.

Linda recently finalized the process of adopting 3-year-old Billy, who had been removed from three previous placements because his needs were termed "overwhelming." Billy was born exposed to methamphetamine and marijuana, and was abandoned in foster care by his birth mother. He was orally defensive and would not eat; he had motor delays and was non-verbal. He was described as active, aggressive, and having a low frustration tolerance and attachment difficulties. At 11 months, he had trouble holding up his head or rolling over.

Linda Hargreaves and sons Ricky (left) and Billy. Linda adopted both children through AASK.

Most of Billy's issues have resolved over the year he has been in Linda's home. Although it took six months, he now loves to cuddle and is very affectionate. According to Linda, he is a sweet little boy who enjoys playing with his big brothers, and he eats up a storm. He receives special assistance through Regional Center case management and at school, where he also receives occupational, physical, and speech therapies.

Reaching out to kids with challenges is not new to Linda. While she was a single mom to a teenage daughter, Linda had her first experience with adoption. She welcomed Andy and then Ricky, who both have a range of delays and disabilities, including cerebral palsy, learning disability, speech delay, and visual impairment.

Linda is a great advocate for her kids and for other parents, too. She educates herself by reading books about topics such as FAS and challenging kids, and applies the techniques she learns. She participates in a chat group about FAS on the Internet. She makes sure that the kids receive what they need from school, and she serves on an early intervention school board to see that other parents receive support.

cated to finding homes for these children, who are often called "unadoptable," and the agency continues to answer this challenging call today.

AASK is a private, nonprofit agency committed to increasing public awareness about the need for adoptive families through events, legislative action, and the media. Staff members make presentations to community groups and publish two quarterly newsletters. Specifically for adoptive parents, AASK holds monthly workshops, quarterly parent preparation trainings, free family events, and parent support groups. Staff are available on an ongoing basis to help our families, wherever they are in the adoption process.

Putting children and parents together

The number of waiting children across the country is enormous: It is estimated that 125,000 children need adoptive homes. Twenty to twenty-five percent of these reside in California. The need for parents to come forward is immense. Many people question whether they might meet the qualifications or standards to become adoptive parents, which may prevent them from coming forward. To increase the number of available families, AASK promotes Equal Opportunity Adoption. This philosophy encourages inclusion of a diverse range of parents. Despite variations in age, ethnicity, marital status, sexual preference, or physical ability, all individuals should be considered as potential adoptive parents.

AASK encourages parents to experience the gifts and challenges of children with disabilities and to share their knowledge and skills with these waiting children.

If you know a family who lives in Northern California that is interested in adoption (AASK's service area is 21 counties in Northern California), AASK invites them to attend the next adoption workshop. Families in other areas are encouraged to contact a local, licensed adoption agency. Adoption gave Billy the opportunity to shine. All waiting children deserve that chance. ■

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Circle #47

AVOIDING CUSTODY RELINQUISHMENT

NO GOOD CHOICE

by Susan Badeau

In order to receive funded services for their children, some parents of children with special mental health needs have been told they must give up custody of their child. But legislation exists that protects parents from this "Catch-22" situation.

"If you want mental health services for your child, you have to beat 'em up, lock 'em up, or give 'em up." So say parents and advocates for children with mental health needs in states from Colorado to West Virginia, New York to North Dakota who are facing this unconscionable approach when they seek support and services for their children.

And around the country, parents are answering back, "People shouldn't have to break up their families to get the care their children need."

There is a crisis in our child welfare system. Over half a million children are in foster care, and many of them have special needs, including mental and behavioral health needs. The system is groaning under the strain of trying to provide appropriate care for these children, in the "safe, stable, and permanent" settings required by the recently enacted Adoption and Safe Families Act. Meeting the physical, medical, and emotional needs of children who truly have been abused, neglected, or abandoned is already taxing the system. It is not a system that needs to add children who have dedicated, involved, and non-abusive parents.

Yet, this is often the case. Parents of children with mental health needs are told at an alarming rate (one in four according to a recent study released by the National Alliance for the Mentally Ill) that they must relinquish physical and legal custody of their children in order to get the services they desperately need.

Some of these children, like Brian, age 5, are very young. Living in Indiana with his grandparents, Brian has a string of diagnoses including attention deficit-hyperactivity disorder (ADHD), oppositional defiant disorder (ODD) and post traumatic stress disorder. Others, like Melanie, are teenagers, whose risk of suicide is particularly high. Melanie has been diagnosed with clinical depression and social anxiety disorder, and is frequently suicidal. Altogether, an estimated 12 percent of all children under the age of 18 have mental or behavioral disorders.

In Indiana, Brian's grandparents went to court in order to get services for him that were not available in their community. A knowledgeable judge made it possible for Brian to receive such services without forcing his grandparents to relinquish legal custody. Yet, in Pennsylvania, Melanie's parents were told that the only way they could obtain the residential services Melanie requires in order to remain safe, was to give up custody to the state. They were told this in spite of the fact that Pennsylvania, since 1991, has had a procedure in place to ensure that children like Melanie can become Medicaid-eligible and receive residential mental health services paid for by Medicaid without being placed in state custody.

Why are families being asked to make these dire decisions? While there are a number of complex reasons, most come down to money. Medicaid, through the EPSDT (Early and Periodic Screening, Diagnosis, and Treatment Program) requirements, must provide for the diagnosed mental health needs of Medicaid-eligible children. Yet, it is an income-based program and many families do not meet the strict income requirements to obtain Medicaid for their child. Therefore, when a family's private health insurance will not pay for the treatment a child needs, and the family income is too high to qualify for publicly-funded medical assistance, relinquishing custody is seen as the only option. Many states tell families that the only way they can access funds from Title IV-E (child welfare money) of the Social Security Act in order to legally fund Medicaid-provided services to these children, is if the children are in the state's custody.

In addition to funding issues, confusing lines of authority and jurisdiction for meeting the treatment needs of children with mental health challenges add to the problem. These children often slip through the cracks of multiple systems including special education, juvenile justice, and healthcare delivery systems. Social workers, often lacking in training and burdened by high case loads, may not know about all of the options available and therefore inadvertently provide inaccurate information to parents, as happened in Melanie's case.

Alternatives do exist. For example, children do NOT have to be in the state's custody in order for a state to use Title IV-E dollars to provide services for that child. A voluntary agreement between a parent and the child welfare agency is sufficient. This allows the parents to retain decision-making and other roles and responsibilities in their child's life.

Medicaid also provides alternatives, through programs such as the Katie Beckett Waivers (also known as TEFRA) and the Title 1915 waivers. Both are options, within Medicaid, that allow states to pay for services to children in their own homes or communities without requiring that the parents relinquish custody. Sometimes, residential or other services can also be provided through a child's Individual Educational Plan (IEP) under the Individuals with Disabilities Education Act (IDEA).

In spite of the options and alternatives that exist, families are still being told that they must relinquish custody to obtain services. Parents of children with severe emotional disturbances are often exhausted, physically and emotionally depleted, and financially drained. They are holding onto their own sanity by a thread, and not only have to be concerned about the needs of the child with the emotional challenges, but the safety and emotional needs of the other children in the home. Therefore, when they are confronted with the decision to place their child in custody in order to receive services, or to face surviving on their own with no or limited services, they are often desperate enough to make the relinquishment decision.

This is a problem that not only faces biological families of children with mental health challenges, but can also impact the families who adopt such children from the foster care system. After having met all of the requirements to adopt, and opening their home to a youngster with special needs, families seeking intensive mental health services are frequently told to "give the child back" to the foster care system in order to obtain these services.

Both biological and adoptive families need to know that they should NEVER be forced to relinquish custody of their child in order to obtain services. While many more changes are needed in both law and practice, alternatives currently DO exist to help families in these situations, and there are resources families can turn to for help. The Bazelon Center for Mental Health Law, together with the Federation of Families for Children's Mental Health, has recently published a booklet entitled "Staying Together: Preventing Custody Relinquishment for Children's Access to Mental Health Services—A Guide for Family Advocates," which offers many strategies that both parents and advocates can use. The booklet can be obtained through the Bazelon Center, (Web site: http://www.bazelon.org or by calling [202] 467-5730.) Another resource is the National Alliance for the Mentally Ill, (Web site: http://www.nami.org, or phone: [703] 524-7600. Adoptive families in need of support can contact the National Adoption Center's AdoptNet, (Web site: http://www.adoptnet.org, or [800] TO-ADOPT [862-3678].) ■

Social workers, often lacking in training and burdened by high case loads, may not know about all of the options available and therefore inadvertently provide inaccurate information to parents, as happened in Melanie's case.

Susan Badeau has been a child advocate and child welfare professional for 20 years. She recently completed a one-year Kennedy Public Policy Fellowship in Washington, DC, where she had the opportunity to work on policies that impact on the lives of children and families, including the recently enacted John Chafee Foster Care Independence Act of 1999.

Active in efforts on behalf of children and families with special needs, Sue serves as a Policy Consultant and Regional Coordinator for Family Voices, a Policy Consultant for the Casey Family Program, Chairperson of the Education and Training Committee for the Delaware Valley Adoption Council.

Sue and her husband, Hector, are the parents of 22 children—Aaron, Alysai, Adam (deceased), Wayne, Todd, Dylan, Geeta, Joelle, Raj, Isaac, Chelsea, Flory, George, Jose, Sue Ann, Abel, David, Trish, Renee, Lilly, Fisher, and JD—two by birth and 20 who are adopted. The family's story appears in "Angels Among Us" on page 28.

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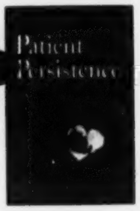

This book celebrates the ability of people to overcome obstacles to achieve their goals. The author, Adele Gill, is a certified disability analyst, a Fellow of the American Board of Disability Analysts, and an advocate of inspirational and motivational self-help. Ms. Gill has divided the book into two sections, Hope and Courage. Both contain selections that deal with turning points in people's lives, times when they found strength, hope, and the courage to persevere in the face of adversity. This book offers help and hope to those who feel that their lives are out of control or that things have gotten so bad that there will never be a way to make them better. Through examples from the lives of real people, this volume demonstrates that there is always a way.

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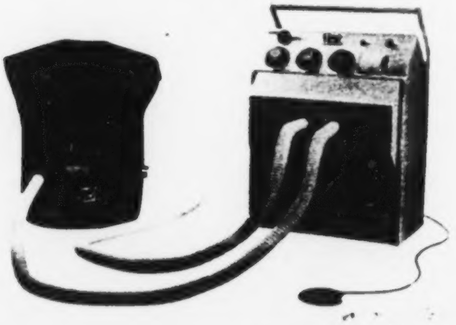

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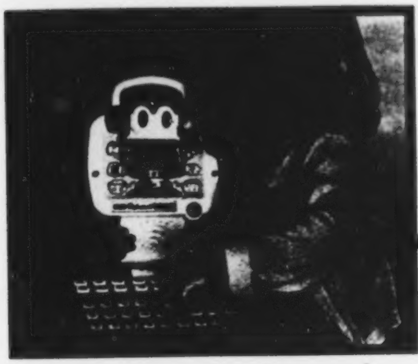

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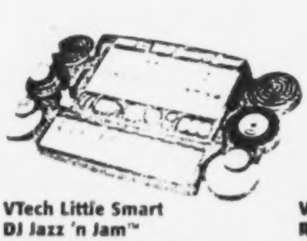

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SATISFYING THE CURIOUS

What to do when those questions and stares come your way

by Jodi Buchan

As parents of children who may stand out from the atmosphere of perceived "normal," we have all had encounters of the "curious" kind.

These encounters happen when we're rolling through the grocery store aisles or as we're being seated in a restaurant. Necks stretch in curious wonder, eyes follow then swiftly avoid contact, tiny fingertips reach to point. Sometimes these curious encounters are offensive and sometimes they are with sincere intent. The genuine ones catch your eyes and smile, say hello to your child without expecting a response, want to know your story, your child's story.

The question is how to handle the curious on our terms. Here are some strategies to help you have encounters of the meaningful kind.

Epic to overview

• Our experiences raising children with special needs can include complicated, lengthy histories. When responding to the curious, ask yourself these questions:

How much time do I have?

How much do I want them to know?

How can I engage my child in his/her own story?

Adapt you answer to the environment (time, surroundings) in which the question is asked, along with the question itself. Respond with a brief overview.

• Kill them with kindness. The curious are occasionally caught with their eyes glazed and their jaws down. Direct eye contact and an enthusiastic greeting, verbal or non-verbal, can snap them out of it. A smile instead of a snarl can go a long way to help your community's awareness.

• Punch lines. Having a few prepared one-liners to recite can put borders on the intrusions into your privacy, keep your sanity, and help you to advocate for your child. Match lines to a situation, such as stares during a grocery store episode: "I can't stand spinach either." Or, the in case of inappropriateness, "Thanks for asking, but it's not the right time." If your child has language, you can even practice a canned line or two for them to respond with like, "Hi, my name's Katie." It aids in communication skills and after all, though some occasionally forget, introductions are the appropriate way to start a conversation. For curious little ones, scale your response down to their size. When they stand mystified near my daughter, I tell them, "She has a hurt brain and needs a little help playing." Most children immediately approach her and even begin to tell her things like, "Don't eat the dirt." (Bonus: These tips from peers are infinitely more effective with my daughter than when I say it!)

• The Sandwich technique: Positive-point-positive works well to reeducate the unfamiliar. You might begin by thanking the person for asking about your child (positive), followed by explaining how you don't believe any thing is "wrong" with your child—we just have different challenges (point), and conclude by indicating how nice it is (positive) to have someone ask questions instead of staring.

Message in a T-shirt

• Don't feel like talking, but you have something to say? Wear a statement T-shirt. In our case, t-shirts allow my daughter who has no language to have a voice. She has one from the SMaRT therapeutic horseback riding center, which states, "Challenge Your Abilities." Statement shirts can help you and your child communicate to the curious without imposing interruptions.

- **Classroom visits.** A parent or guardian can help satisfy those most influential and curious in your child's life: your child's peers. Discuss a classroom visit with your child's teacher. Explain your child's history to the class. Ask what about your child is different from them, ask them what is the same. Dialogues can help your child's classmates break down the "curious barriers" and make the school environment more supportive.

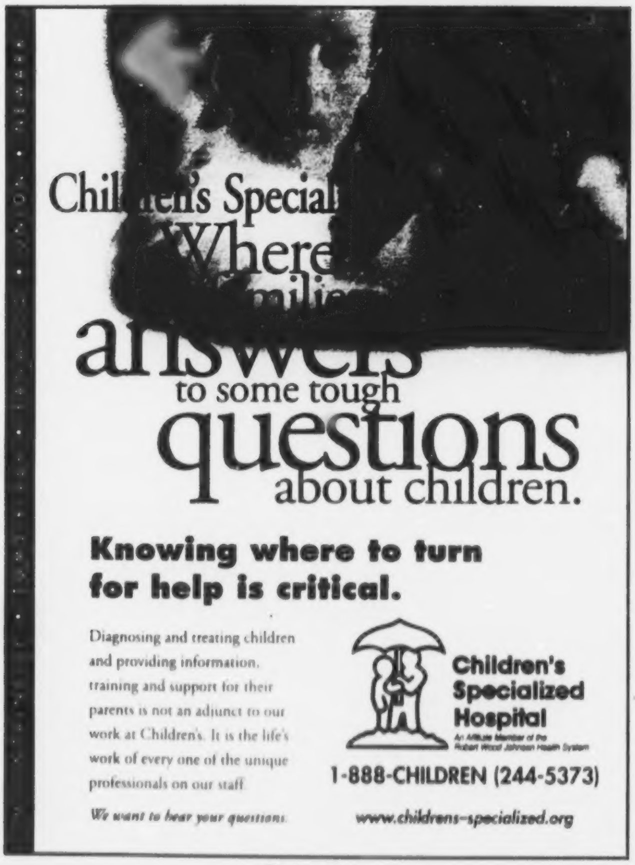
- **Language of labels.** Even those who are well-intentioned often don't use "People First" language; they unknowingly say offensive things. You might hear, "Wrong with—Confined to—Suffering from—Retarded." Try to focus on the intention rather than the method. The uneducated curious might "suffer from" a lack of exposure to language we use in our everyday lives.

- **Get them involved.** There are a few insatiable curious who really want to know more, to understand, maybe to become involved. They may have even shared a story of a relative, of a course in school, or simply voiced heartfelt empathy. The best way to funnel this curiosity is to recruit them to volunteerism. They can become involved in the Special Olympics or a potential respite provider. You can direct them to public service in your community, helping them to contribute to programs your child needs.

- **Be your child's ambassador.** You are often the liaison between your child and your community. There are people who approach our families to learn more about us. Some people who don't approach us might want to, but don't know if it's "OK." Still others form opinions, or opposition, by just observing. How you act and react when you're with your child in public can shape perceptions of your child and the disability community as a whole.

Recognizing we are under no obligation to satisfy the curious, opening up to those eager to learn and to those who fear the unknown, can aid in subduing alienation and isolation of our families. ■

Jodi Buchan is the mother of Katie, 14, who has a disability. Jodi is also the NW Regional Health Care Program for Children With Special Needs (HCP) Family Advocate and Routt County Part C Coordinator in Colorado.



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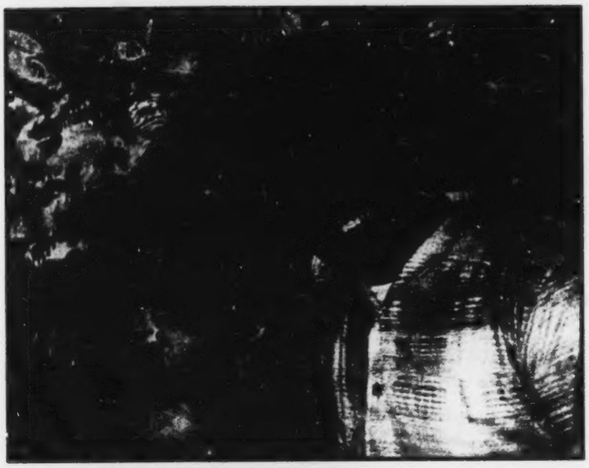
Mindy recalls Allan's excitement, as he ran into the kitchen and said, " 'Ma, Ma, Ma! Guess what? There's an opening for me in a new house!' "

A MOVE TOWARD INDEPENDENCE

by Philip H. Levy, PhD



Mindy and her son, Allan. While Allan will now be living independently in a group home, he and his mom will always be "buddies."

A single mother raising a child who has a developmental disability has an overwhelming responsibility. Mindy F., of Brooklyn, New York, however, was also caring for her mother, whose health was deteriorating.

Mindy has faced this situation for the past 24 years, and she has handled it with considerable strength and ability. It definitely helps that Mindy and her son Allan have a close, friendly relationship and truly enjoy each other's company. "He's my buddy!" says Mindy.

As Mindy's mother's health worsened after a stroke, Mindy grew increasingly concerned about the amount of time and energy that Allan spent caring for her. Although Allan loves his grandmother and wants to help her, the level of support that she needs far exceeded what Allan could provide. Allan's devotion to his grandmother made it difficult for him to take care of his own life. He started missing days at his day habilitation program and skipping important therapy and socialization groups.

Seven years ago, Mindy and Allan began receiving counseling, medical, and other services with the help of a social worker from YAI/National Institute for People with Disabilities. Among the primary goals of counseling was to prepare both of them for Allan's eventual move into a group home.

Allan's dream of achieving greater independence came closer to fruition when a new YAI residence was being developed in a nearby Brooklyn neighborhood. Mindy recalls Allan's excitement, as he ran into the kitchen and said, " 'Ma, Ma, Ma! Guess what? There's an opening for me in a new house!' " Mindy greeted the news with mixed emotions. On one hand, she felt that moving away would allow Allan to develop his life skills and promote independence, on the other hand she thought, " 'Oh my God, he's going to leave me.' "

Overall, however, Mindy was thrilled for Allan, and went to take a look at the new place while it was still being renovated. Mindy says, "I thought immediately, 'This is really nice, it's roomy, and in a great area.' "

Allan's eyes light up as he talks about having his own room, with his own phone and television. He'll be able to spend time with the other five residents when he chooses, both in the house and during community activities. Allan is also looking forward to doing a lot of cooking in the house's newly-renovated kitchen. "I like to cook desserts

continued on page 52

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Once a month, parents and other family members join the group to share any thoughts or concerns about the move. As one parent of an adult child living in a group home explains, "Letting go may be the best contribution to the future growth of a son or daughter that a parent can make."

continued from page 50

like strawberry shortcake with whipped cream and brownies." And, if Allan decides he wants to invite his Mom over to try some of his famous strawberry shortcake one night, she's only a 10-minute bus ride away.

Allan will work on acquiring other skills while living in the residence, including learning to travel independently around the new neighborhood. He already travels on his own to a work readiness program where he is in the process of finding a job. The staff will also help him fit his new job into his daily routine, working on punctuality and dressing appropriately for work. Allan also wants to learn money management, and he'd like to join a gym. These are all important life skills that will help Allan build a fulfilling and meaningful life for himself.

The neighborhood is close enough that Mindy and Allan are already familiar with it. "Allan used to play soccer near there when he was a kid," Mindy explains. "We know people there. And the neighbors are very thoughtful and accepting. Someone actually came up to us while we were looking at the house, just to welcome Allan to the neighborhood."

Fred Feibusch, YAI's Director of Residential Services for Manhattan, Brooklyn, and the Bronx, says that finding a neighborhood with an accepting attitude is a crucial part of the process when seeking a site for a new group home. "We look for a neighborhood that's going to be a safe and pleasant environment for our residents. It's important that they feel part of the community, and that the surrounding community understands that we're going to be great neighbors, too."

To help Mindy and Allan deal with the pending move, YAI provided Mindy and Allan with group therapy. This enabled them to address the emotions involved in this important transition.

In Allan's group, the six soon-to-be housemates got to know each other, and talk about their own feelings related to the move. A therapist, who also helps them to discuss practical issues related to living together, facilitates the group discussions. "We figure out how we're going to get along," Allan explains. "We're all going to help out in our new house—like maybe one week it'll be my turn to take out the garbage, and next week it's someone else's turn. Things like that." He says the therapist helps them with any fears they have about moving away from their old homes. "She tells us, 'You don't have to worry. I know you're going to miss your Mom, but it's going to feel good to move on.' "

Once a month, parents and other family members join the group to share any thoughts or concerns about the move. As one parent of an adult child living in a group home explains, "Letting go may be the best contribution to the future growth of a son or daughter that a parent can make."

Mindy says that the group has really helped her deal with her feelings about Allan moving out. "Even now," she says, "knowing what a great life he's going to have in this new house, it's hard to let him go. So it's good to talk with people who are in the same situation." This network of support will still be there for Mindy after the move, and she is already forming bonds with the other parents.

The new residents also get acquainted in less formal ways through events such as a recent bowling trip. Sharon Hogan, YAI's Senior Residential Supervisor for Brooklyn, explains that it's easier for the group members to talk to each other when they're doing something they enjoy. "When we all went bowling, it was amazing how everyone started to open up to each other, and to really talk about moving into the new house." Sharon says that these kinds of activities help the group to feel less nervous about the move—rather than feeling as though they're moving in with a group of strangers, they're excited to spend more time with new friends.

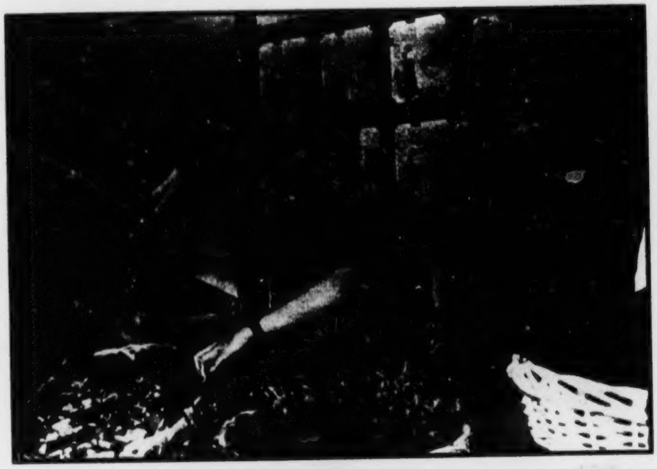
Because Allan's caseworkers were so closely involved with him and his mother over the years, they were able to find a home for him that truly met his needs as an individual. Allan has the chance to gain much-needed independence without losing contact with his close, loving family. And his mother is assured that Allan has a safe and happy home where he can be himself and grow as an individual. "He's looking forward to exploring the new opportunities that come with moving out and moving on," Mindy says. ■

Philip H. Levy, PhD, is President and Chief Operating Officer of YAI/National Institute for People with Disabilities.

GIFT WITHIN A GIFT

A non-profit business provides customized presents and inclusive employment opportunities

by Joel M. Levy, DSW



General Store employees create custom designed gift baskets.

Having a job that's right for you is one of the most important things in life. Just ask Jessica Campbell. For a long time, Jessica felt unfulfilled in her work. This bright and energetic 26-year-old who has a mild developmental disability, has been through job training and has had a range of employment experiences.

While Jessica felt she had the ability to perform a variety of jobs, her employers focused only on her disability and didn't provide her with enough challenges. Her talents ignored, Jessica often felt unhappy and unappreciated. "They weren't interested in what I thought," she says. "They just shoved boxes at me."

Happily for Jessica, five years ago a supervisor at her group home found out about a new option. YAI/National Institute for People with Disabilities was about to start a non-profit mail order business called the General Store, which was specifically designed to create employment opportunities for people with developmental disabilities.

Through a catalog and Web site, the General Store offers tax-free gift baskets filled with goodies from chocolates to gourmet coffees to home spa products. While edible goodies are among their most popular offerings, the General Store also custom-engraves plaques and other items, and acts as a fulfillment house for companies such as 1-800-FLOWERS. They have a range of items to fit every budget, and they thoughtfully custom-design each package. Recently, a customer ordered a unique gift for a friend who was moving into a new house—the General Store staff filled a toolbox with tape, tools, and other useful housewarming items.

Jessica visited the General Store headquarters and loved it. So from the very first day of operation, she became part of the General Store team. The employees at the site receive orders from customers, design baskets to fit their needs, arrange them decoratively, and ship them. the customers not only receive these lovely baskets, they also help to create a job for someone with a disability. It's a gift within a gift.

Today, Jessica still works at the General Store, and enjoys her work just as much as she did back then. No longer feeling unappreciated and unfulfilled, as she'd been in her previous workplace, Jessica has a great relationship with her supervisors and co-workers. "I like everybody here—they're very nice and helpful. They listen to me when I want to make suggestions or change things. And I've gained a lot of new friends here—I think I can say that they're the nicest people I've ever worked with."

For Joan Leinwand, general manager, working with Jessica and the rest of the General Store staff is also a pleasure. Joan says, "There's no greater pride or joy than seeing the individuals that work here become productive, tax-paying citizens."

Over the years, Jessica's job at the General Store has also given her the chance to grow and to learn new skills. Jessica's always open to new challenges and loves to share her knowledge with others. "I've learned how to use different equipment here, like the shrink-wrap machine," she says. "Now when new employees come in, I'm the one who teaches them how to shrink-wrap packages."

Clearly, this fulfilling work experience has made a huge difference in Jessica's life. It has boosted her self-esteem as well as allowed her to become a more productive and independent member of the community.

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Circle #59

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Many businesses today, however, are discovering that hiring people with disabilities is a sound business decision. In this spirit, the General Store staff would like people to order from their catalog because, first and foremost, their products are competitive. As Michael Kramer, Director of YAI's Employment Initiatives Department explains, "Individuals and businesses order from the General Store because we offer terrific products and outstanding service. The fact that we are providing much-needed job opportunities for people with disabilities is really just an added bonus."

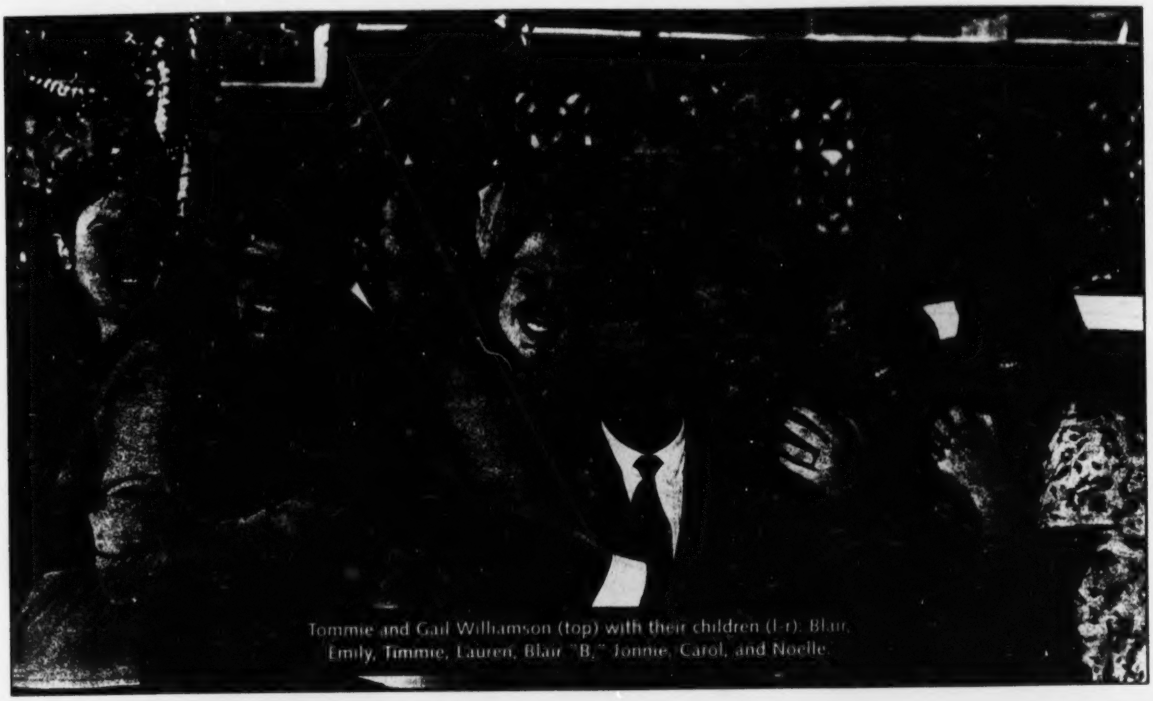
Rashawn Smith heartily agrees. This 29-year-old, who has a developmental disability, takes great pride in the products he helps to create at the General Store. He's also proud of the independence he's gained during the four years of his employment there. Before coming to the General Store he held a series of part-time jobs which left him with little pocket money. He now works full-time, and uses his paychecks to buy clothes, to go to the movies, and—just like all of us—to pay his bills. "I pay my own cable bill," Rashawn says proudly, "so that I can get the channels I like to watch. But I put some of my paychecks in the bank. I'm trying to save up money so that I can be more independent."

Earning money gives us the simple but vital freedom to make these types of choices in our daily lives. For many people with developmental disabilities who haven't always had that freedom of choice, a weekly paycheck becomes a passport to a whole new world of options. Rashawn recently went on a long-anticipated trip to Disney World, where he used his earnings to purchase all his own food and souvenirs. But he didn't just buy things for himself. "Joan [Rashawn's supervisor at the General Store] really likes gorillas, so I brought her a stuffed animal gorilla from Disney."

Choosing a gift from the General Store can also make the act of giving more meaningful. During the busy holiday season, for example, we are often so harried by the difficult task of choosing, buying, and sending gifts that the true meaning of the holidays becomes obscured. The General Store's gift catalog offers a welcome solution to that dilemma. First, it allows customers to shop from the comfort of their own home or office. More importantly, every item purchased through the General Store is accompanied by a card that highlights two unique aspects of the gift: that it was custom-designed for the recipient, and that it created employment opportunities for people with developmental disabilities. It's a special way to show you care. ■

If you'd like to receive a catalog or place an order, call 1-800-YAI-9914, or visit their Web site at http://www.generalstoregifts.org. Gifts can be shipped anywhere in the world. The General Store is a not-for-profit business, so sales tax will not be charged.

Dr. Joel M. Levy is Chief Executive Officer of YAI/ National Institute for People with Disabilities, an award-winning network of not-for-profit health and human services agencies serving over 15,000 people with developmental and learning disabilities.



Tommie and Gail Williamson (top) with their children (l-r): Blair, Emily, Timmie, Lauren, Blair "B," Jonnie, Carol, and Noelle.

role models

A "CLASS ACT"

Gail Williamson gives a positive spin to the term "stage mother," helping develop self-esteem far and wide within the community of performers with special needs.

by Vanessa B. Ira

When Gail Williamson's son Blair was 4 years old, he did something that marked a significant moment in his and his mother's lives. Following a series of developmental tests with a psychologist, Blair, who has Down syndrome, turned to the nearby observation wall that was disguised as a mirror. Spying his own reflection, he took a bow, apparently unaware that an "audience" composed of clinicians was watching from the other side of the wall.

Though he may have been a young boy then, Blair demonstrated that an actor, as with most people, likes to take pride when viewing his own reflection—whether it be in the mirror, or through inspiring portrayals in films, television or shows. When Blair broke the so-called theatrical "fourth wall" and bowed, he was proudly saying to his imaginary audience: "Hey look, here I am!" It was as though Blair, now 21, had presciently acted out Gail's life's work for people with special needs.

For more than a decade, Gail has been advocating on their behalf by educating casting directors and agents on the idea that the best actors to play people with disabilities in the media are people with disabilities. She is the Talent and Industry Coordinator at Media Access Office (M.A.O.), a non-profit partnership of the California Governor's Committee for Employment of Disabled Persons that assists and encourages the accurate portrayal and employment of people with disabilities in the media. Gail has closely worked with the casting directors of TV shows such as "E.R," and "Touched by An Angel," recruited and developed new actors, and lectured for media and disability groups providing education on the growing media trend to include characters with disabilities.

"We need to create positive role models and images of special needs in the media," Gail says. "We have to create openness within the entertainment community while enlightening parents and teachers on how to encourage children with special needs who are interested in performing."

"When parents have children with disabilities, many of them are so overwhelmed that

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> "The inclusion generation is coming upon us, so Hollywood has to be prepared for this."

Tips on Getting a Child with Special Needs into "Show Business"

By Gail Williamson

Does your child have a flair for being in the spotlight? Does he or she like to dress up and be different characters? Dance and sing to music? Enjoy interacting with adults and even strangers? Is he or she comfortable in new situations? Content without being with mom or dad? If you answered "yes" to these questions, you may have a star on your hands. Just make sure that you are pursuing this business for your child's enjoyment and not for self-gratification:

1. The Media Access Office has over 600 actors with disabilities in their performer files. If your child gets Union work through the Media Access, it will find a franchised agent to negotiate your child's contract for you. The service of the office is free. To get your child in thei files, contact Media Access and request a "New Clients" packet. (See below)

2. Search for a "Screen Actor's Guild" franchised agent in your area. The Media Access Office can supply you with a list. Most agents are hesitant to take on a child with special needs because there is so little work out there. Remember, you don't need to have an agent to find work if the child has special needs. The Media Access Office can fill that need. An agent will negotiate your child's Union contracts and take a 10 percent cut, a good deal. An agent will never take an up front fee to represent your child.

3. Find a manager, different then an agent, who will represent children with special needs. The Media Access Office has a few clients who have managers. A manager is not franchised and can take from 15 to 25 percent of your child's earnings; they will let you know their percentage when you meet with them. They are not allowed, by law, to negotiate your child's Union contacts, but many do. If you have both a manager and an agent, they both will take a percentage of your child's earning. No manager should ever charge an up front fee to represent your child.

4. Never sign your child with a management company that auditioned your child at an open call, later calls to say they would like to represent your child, and at a private appointment tells you what it will cost you for classes and photos. This is a scam that goes on every day. Call the Media Access Office for advice when doubt.

5. Train, train, train. Get your child into acting classes. Ask around, you may find a class at the park or you may get you child into a local children's theatre group. This is a wonderful avenue for full-inclusion. See if your community or state has an active VSA Arts Program (see below), they may offer acting classes and opportunities. Acting for children is like participating in Little League. They have to practice and be ready for the game at all times.

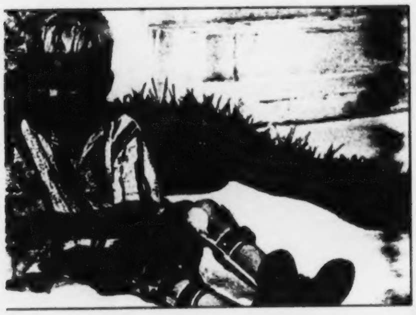
6. Encourage good hygiene. Help your child learn to always be well-groomed. Get your child a good haircut. Keep skin clean and moisturized. See the dentist regularly. Keep nails clean.

7. Adaptive equipment can become "adaptive props." Keep some old equipment, just in case. Your child might use a walker consistently, but keep that old wheelchair in case a part for a child in a chair comes along. Adaptive props can be listed on the child's resume.

8. Be ready to stop whatever you are doing and go on an audition immediately. That is how this business works. Most parents of children with special needs have developed a lifestyle with support from friends and employers so that they can go at a moment's notice when their child has a medical need. The auditions will be few and far between. It may be two or three years, if ever, before you have the opportunity for your child to audition. So when it happens, drop what you're doing and go!

9. If you live in the state of California or your child's contract is written in California, there are some very good laws that protect your child. Your child will need a California entertainment work permit. If you live outside California, it is best to contact your state's Department of Labor to see what laws, if any, will apply to your child. The Media Access Office can give you the number for your State Department of Labor.

For more information, contact the Media Access Office at 818-752-1196; 818-509-5614 TTY. 4640 Lankershim Blvd., Ste. 301, No.Hollywood, CA 91602. http://www.gcedp.org. Contact VSA Arts at 1300 Connecticut Ave. NW, Ste. 700, Washington, DC 20036. Phone: (800) 933-8721; Web site: http://www.vsarts.org; e-mail info@vsarts.org.



Actor Alan Toy (above, and as a young boy), who had polio as a child, advocates for inclusion of people with disabilities in the media.

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they tend to lose vision for the child's future," actor Alan Toy observed. Alan contracted polio at three in the early 1950s while living in Key West, Florida with his family. He carved his own future by earning multiple degrees in theater and embracing an acting career. Alan also became a social activist, child counselor, and advocate for actors with special needs during Media Access's beginnings in the early 1980s. He has had roles in "M.A.S.H.," "Born on the Fourth of July," and dozens of other parts on TV, films, and the stage. Alan describes his line of work as being an empowering experience, helping to give the disability community "validity to have our voices heard." Others in the entertainment industry agree.

"What Gail is doing is remarkable and important," says John Wells, executive producer for the TV series "E.R." "Using actors without disabilities to play characters with disabilities should be unacceptable in Hollywood today as suggesting that white actors in black face play African-American characters."

"Mother of the Year"

Many have taken notice of her particular

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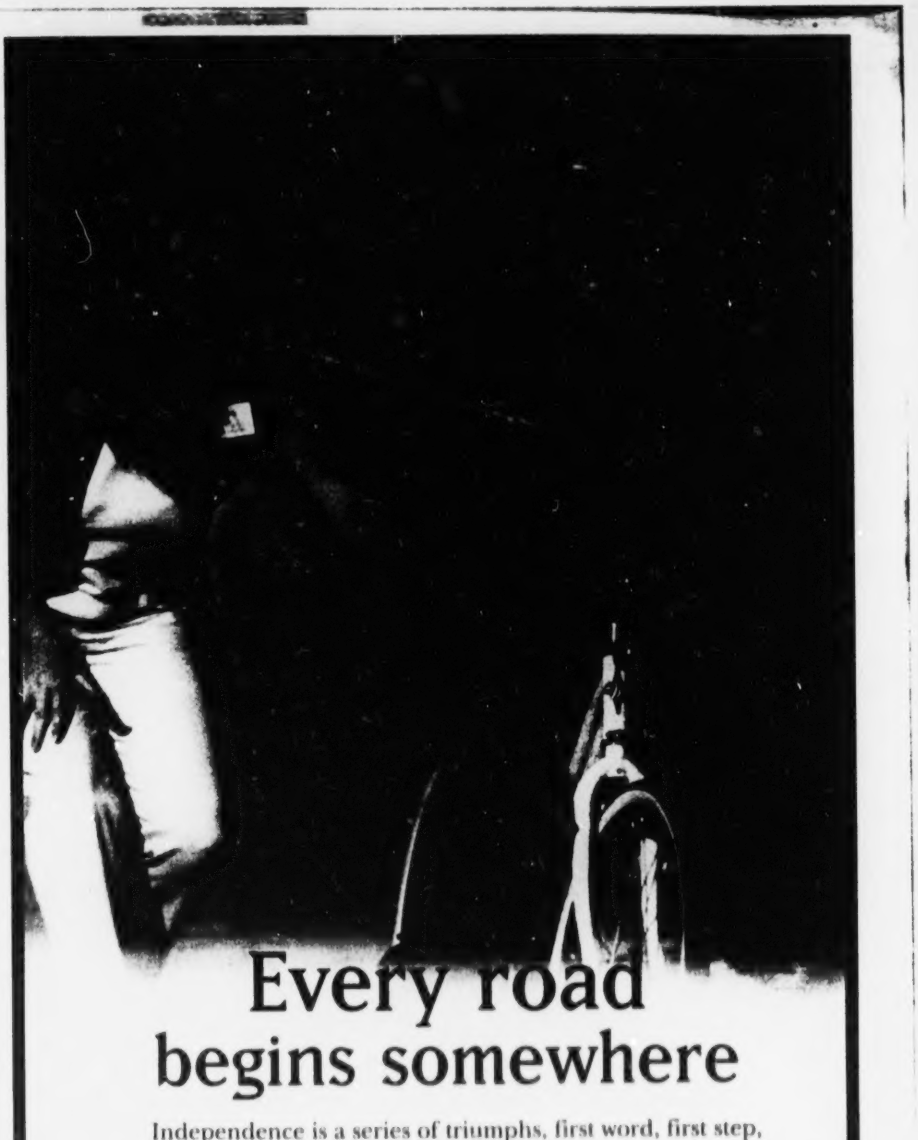

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Young actors (l-r) Jawana Derios, Keighly Ruiz, Brianna Del've, Kaylind Ramos, and Carry Harvey, celebrate the end of a day of filming of Disney's "Special Olympics Volente-ear Hugger" commercial along with Gail Williamson, and Jon Turtletaub, Director.

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knack for helping develop self-esteem and self-fulfillment. In 1999, Gail was singled out as the "California Mother of the Year" by American Mother's Inc. This is evident not just in her role as Blair's mother, but through her heroic maternal efforts in and out of the disability field.

"Ultimately, all children have special needs," Gail has said. In 1995 Gail and her husband, Tommie, legally adopted her six nieces and nephews, the orphan children of Gail's half brother who died of melanoma, and his wife who had died of Lou Gehrig disease. The six teens, now aged 14-25, joined Blair and his older brother Tim, 24, in completing the Williamson household.

The thought of five years of juggling the emotional and practical needs of eight adolescents may seem daunting to any parent. Yet, Gail met the challenge while attending to Blair's acting pursuits and those of many other young performers with special needs. Blair has been a professional actor for half of his life. He was 10 when he first saw Chris Burke, who also has Down syndrome, star in his own television show "Life Goes On." That was when Blair got serious about pursuing a professional acting career and, since then, Gail has solidly stood by Blair.

Gail takes on the active role of "stage mother" not just for Blair, but also for so many other children who wish to perform. Her excitement brims over when she discusses new films or shows which have employed people with disabilities: "Pumpkin," "Jewel," "C.S.I," and a Hallmark commercial called "Dave's Place." These days, Media Access has 90 children and adolescents, ages 2-18 in its file, and Gail is heavily involved with many of them.

The California Governor's Committee for Employment of Disabled Persons highlighted Gail's talent as a self-motivator, allowing "her to use these skills with all levels of people within the industry. She works closely with directors, writers, actors, whomever it is that makes things happen for her clients."

Perhaps the very thing that buffers Gail in

Gail and Blair Williamson.

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her extremely involved life is her practicality. Though she strives to achieve the ideal in her work, she is very much a realist, as can be gleaned from the "Parenting Creed" that Gail keeps as her guide: "Life isn't fair. Things are not always what they seem. Each child is an individual creation affected by outside stimulation that is sometimes beyond your control."

"Vision Quest"

"The inclusion generation is coming upon us, so Hollywood has to be prepared for this," Gail says. "Unlike generations past, this one has been in school and in the community with children with disabilities. Just think, those classmates or friends will one day become employers. For those who will be leaders in show business, they will be aware of the importance of including people with disabilities and allowing them to make their own contributions as actors, or as behind-the-scenes professionals. We want to make sure that we have enough skilled people with special needs for that eventuality."

In typical forward-looking fashion, Gail wants to see the day when the need for a Media Access Office will no longer be necessary. When that time comes, Gail will once again involve herself in other pursuits that have an impact on many lives. The C. Morley Sellery Special Education Center in Gardena, California apty described up Gail's contributions: "It is truly amazing what one mother's vision for her child and others with disabilities can do for the disabled as a whole." ■

Above: Blair appeared on television in "My Antonia."
Above right: Blair (top left) with fellow actors Chris Burke and Christopher Stevenson.

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Circle #63

Celebrating the Holidays With a Child Who Has Special Needs

PHOTO COURTESY OF PHOENIX PEDIATRICS, LTD.

Santa pays a visit to Megan, who has a disability, and her little sister, Amber.

by Kerry Pianoforte

Holidays offer families a time to get together and share in fun family traditions. This time of year can also be hectic and stressful. For parents who have children with special needs, the daily demands of raising their child, compounded with the added demands of the holiday season, can just be too much to handle. Some simple tips may help parents to relax a bit and enjoy the season. According to Kevin Berger, MD, a pediatrician with Phoenix Pediatrics, Ltd., Arizona, who sees many children with special needs, "One of the most important things is that the child with special needs participates in the joy of the holidays. Family and friends should be aware that while they do have special needs, these kids are contributing in a very normal way."

Parents may not know how much of their child's medical condition they should share with out-of-town loved ones who may not be familiar with their child's condition. Dr. Berger suggests that "an open and honest attitude helps everybody to understand what the needs are." Parents can provide as much information as they and their child feel comfortable sharing, and when at all possible, the child should be included in the discussion.

Adapting activities to suit all abilities

Children love to be included. Dr. Berger suggests adapting activities to meet the specific developmental level of the child. Simple tasks like holding wrapping paper can help children feel involved. Some other examples of activities include helping to hang ornaments, mixing cake batter, tearing the tape to wrap presents, or just holding the tape. Playing holiday music sets a positive mood and offers the opportunity for children to sing or hum along, or even just sit and listen. Parents can also ask their child how they would like to participate in the celebrations.

Enhancing participation can also include dressing the child in festive holiday shirts or traditional holiday garments, and decorating the child's wheelchair.

Everybody lends a hand

Dr. Berger explains, "Some families find keeping the celebrations in their own home can decrease the amount of work they have to do." Guests can contribute to the celebration by bringing food or helping with the decorations. Having family around can be a huge help. He adds, "It's a nice time for families to just be together and take the focus off the child who has special needs. It gives everyone a chance to participate and simply enjoy the special time with family and friends." ■

Tips for a happy holiday

The following tips were contributed by Phoenix Pediatrics, Ltd.:

- Expose your child to holiday music so the songs become familiar and comforting.
- Let your child sit on Santa's lap—don't be upset if your child is afraid.
- Make sure you are well prepared for holiday visiting. Bring familiar, comfort items for your child; bring your own unbreakable special plates, cups, and utensils. Don't seat your child until the last minute, if they have a short attention span.
- Speak to your host about what your needs will be: dietary restrictions, to be seated near an electrical outlet for medical equipment, a special area for changing diapers.
- Prepare visitors for what to expect. Let them know what kind of behaviors to expect from your child. Let them know about what sounds they may hear, such as ventilator beeps. Prepare other children ahead of time (recommend a book from the library about Down syndrome, blindness, wheelchairs, etc.)

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The Most Beautiful Sound I Have Ever Heard

by Laura M. Fabiani

A portrait of the Fabiani family. Top, (l-r) John, Laura, and Maria, 7. Sitting on Laura's lap are Joey, 5 (left) and Peter, 2. Laura told us that it is rare to get everyone together, sitting still, at the same time.

I remember that first Christmas with my son, Joseph. Born in July, 1995, he was 5 months old. Even though I had a 3-year-old daughter, and knew what Joey should be doing, I still read the first few chapters of the childcare book, *What to Expect: The First Year*, over and over again, until I had practically memorized them. I did not read the information in the middle of the chapters, just the "What Your Baby May Be Doing" part. I started with the most difficult goals first. He wasn't doing any of the things that "your baby may even be able to." So then I went on to what he "may possibly be able to." When that didn't work, I tried "will probably be able to." Still nothing. I gritted my teeth and dug in my heels. One more to go. "By the end of this month, your baby should be able to." Well, we were eight days past the end of this month, and he wasn't able to. I flipped backwards through the pages of the book. I tried other chapters: "The Fourth Month," "The Third Month," "The Second Month." At this point, I tossed the dog-eared book aside, refusing to go all the way back to "The First Month."

What was he laughing at? God? Did God tell jokes? Santa Claus? Angels? We didn't care what he was laughing about. It was laughter.

At 5 months, it was still possible that he was just delayed, but would catch up. Right? He was six weeks premature, after all. I somehow managed to avoid taking into consideration the insult he suffered to his brain. So I mentally wrote my own *What to Expect: The First Year* book. Another month or two and he would be starting to sit up. Another month or two after that, and he would be crawling. Or maybe I should lower my expectations: in another month, he would be batting at toys, or following me around the room with his eyes. Maybe he could simply just laugh out loud. Or, like the book described it, squeal in delight. More than anything else listed in that book, I wanted to hear Joseph laugh.

That first Christmas, Santa brought Joey a push toy. You know, the kind children use when they are first learning to walk. Now, almost six Christmases later, my 2-year-old son pushes it around. Sometimes he walks past Joey lying on the floor, or sitting in his wheelchair.

I remember thinking that first Christmas: okay, so I've tried talking to God about Joey. I fumed at Him that He had kept Joey's twin brother for Himself. Now, give me some help with Joey, God. Make him walk. Make him crawl. Make him sit up. Make him coo or babble. Hello? Are you there, God? Are you listening? It's me, Laura. He never answered. But I kept persisting. Make him roll over. Make him swat at a toy. Make him look at me when I talk to him. When none of these things happened, I figured God wasn't listening. Or maybe He could see my lips moving, but couldn't hear my words since His hands were over His ears.

Since God didn't seem to be interested, maybe I'd try Santa Claus. Maybe he really did exist. Maybe, like in the Chris Van Allsburg book, *The Polar Express*, only those who truly believe could hear the ringing of the sleigh bell. So I believed. And I listened. But I never heard it. Not too long after Christmas, though, I did hear something else.

I started hearing Joey babble. Not your typical babblings of the average child, but his own version. They were very few and far between, but they sounded intentional at times. One night, through the baby monitor, my husband and I heard something we had never heard before. We weren't sure what it was, so we went upstairs and stood outside Joey's room.

It was laughter. Joey was laughing. Belly laughs, squeals of delight. We stood outside his door, and just listened. We laughed too. What was he laughing at? God? Did God tell jokes? Santa Claus? Angels?

We didn't care what he was laughing about. It was laughter. Like the sound of a sleigh bell, it was the most beautiful sound my husband and I had ever heard.

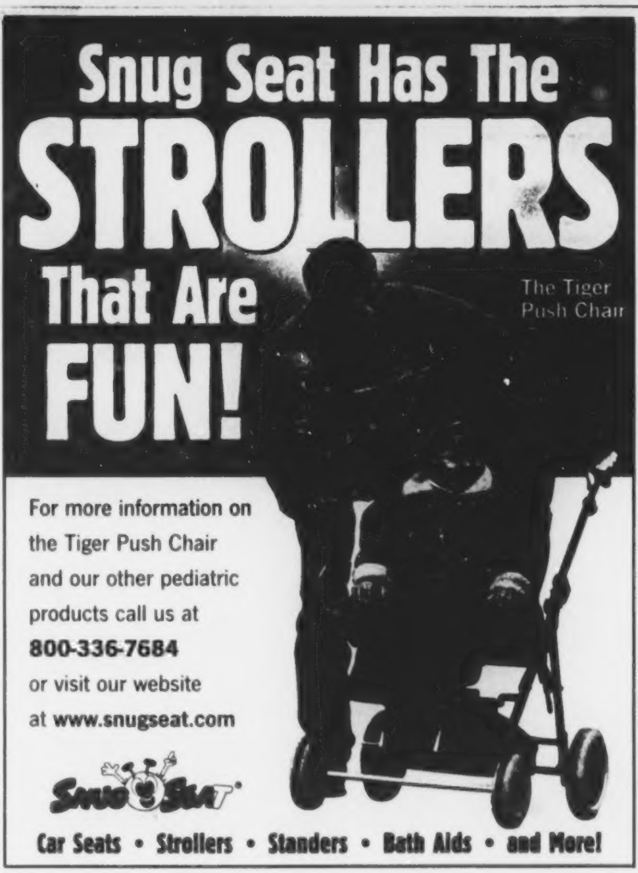
As we approach our sixth Christmas with Joseph, I realize that I don't shake my fist at God anymore. Well, honestly? I do get annoyed every once in a while, but I'm just human. I take Joey to church and he loves it. During the quietest times of the Mass, he usually giggles. Really loud. Must've been a funny one, God.

Joey Fabiani's laughter is music to his parents' ears.

What have I learned in my six Christmases with Joey? That for special needs children, the book should be called, *Expect the Unexpected*. That it's okay to get angry sometimes. That you can rely on yourself, because, among other things, God gave us patience, strength, and a sense of humor. And the ability to utilize all three, sometimes simultaneously.

I also learned that it's okay to still listen for the sound of the sleigh bell. So far, though, I haven't heard it. That's probably because Joey's laughter is louder. ■

Laura Fabiani and her family make their home in Pennsylvania.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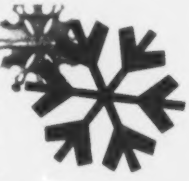
adaptive recreation

Play, Playfulness, and Expressive Activities

by Rebecca Lytle, PhD, and Don Lytle, PhD

The holidays are fast approaching, and for most children, the main attraction is the toys and presents they receive. But all too often, the thrill of the new toys wears off after a few days. Here are a variety of toy-free ways to have fun playing with your child using materials that you probably have in your home already. The play activities in this article can be used throughout the year, do not require batteries, will not break, and can be adapted to suit your child's tastes, personality, and imagination.



Physical playfulness is experienced through the senses and can take a variety of forms. From the moment we take our first breath, we begin to play and learn about our world through the senses. For many children with disabilities, playing with the senses is something they may frequently do to stimulate their various body systems. For example, some children find rocking or swinging to be extremely pleasing, and they may "play" with their vestibular sense (balance) frequently. For another child it might be playing with light and shadows generated by the visual sense. Play is generally spontaneous. However, for many children with disabilities, "facilitating" spontaneity may be necessary. Try the examples listed below and use your own ideas and creativity to see if the power of play comes alive. Although these activities are listed by the primary sense they utilize, most activities are actually multi-sensory. For example, eating pudding can be a way of playing with the gustatory (taste) sense and/or tactile, if one not only eats but also finger paints with the pudding. In fact, for some children richer play may be more fully realized when a combination of these activities and/or senses is utilized.

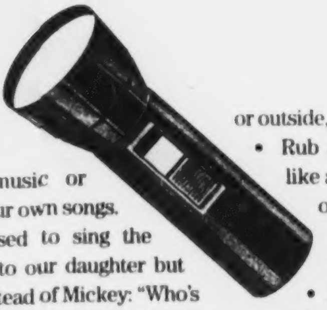
PLAYING WITH THE SENSES

Visual

- Look through books, magazines, and comic strips making up silly stories based on pictures.
- Finger paint with paints, pudding, water, or jello.
- Cut paper into shapes, make snowflakes, or masks.
- Play with flashlights in a dark room and make shadows.
- Play with mazes on paper or create one for the body to move through.
- Use kaleidoscopes, prisms, mirrors, and magnifying glasses.
- Cut shapes on paper bags and then place a flashlight in the bag and turn the lights off. The light will shine through the paper bag and make beautiful shapes around the room.

Auditory (sound/communication)

- Go for a walk and identify the sounds in the environment.
- Listen to different types of music and freely move to the music, sounds, rhythms and/or words.
- Experiment making funny sounds with your mouth or body.
- Read a story that the child is very familiar with and change some of the words. For example, in "The Three Little Pigs," read: "Once upon a time there were three little elephants."
- Make silly faces at each other. You can try to mirror each other or take turns.
- Make up rhythms with your child using your hands, or a stick, or real or homemade instruments. Play along with the radio or tape player. Pretend you are a band.
- Put several different objects into a bag and tell grab bag stories. Each player in turn takes out an item and tells a story about it. The next person takes out a new item and adds onto the story. One long story can be created or indi-



vidual items can each have their own story.

- Listen to silly music or songs, or make up your own songs. For example, we used to sing the Mickey Mouse song to our daughter but inserted her name instead of Mickey: "Who's the leader of the band that's made for you and me? K-E-L-S-E-Y, L-Y-T-L-E. . . ."

Vestibular (balance)

- Swing or spin on a play structure or in a wheelchair.
- Lie in a blanket and swing side to side and/or head to toe.
- Bounce and/or rock on hoppity hops, giant balls, or therapy balls
- Roll in cardboard boxes. Open up both ends and let the child roll inside or in the yard.
- Play on a teeter-totter or slide.
- Players can be pulled around in a wagon, box, or laundry basket with blankets and pillows for support if needed.

Gustatory (taste)

- Play with a popsicle.
- Taste different foods and textures from solid and crunchy to soft and chewy.
- Finger paint with Jell-O or pudding and eat it as well.
- Play with food and then eat it. For example, blow bubbles into your milk, cut up a sandwich into a puzzle to put together, or build a castle and moat out of mashed potatoes and gravy.

Olfactory (smell)

- Go to your local greenhouse or nursery and smell different flowers and plants.
- Smell different foods or scents. Put different smells on cotton balls and put in film canisters. The child can try to identify the smells.
- Smell spices, perfumes, aromatherapy oils, or scented, unlit candles.

Tactile (touch)

- Roll on different textures such as the grass, pillows, or carpet.
- Jump into a pile of pillows or onto a bed, or outside, jump into a pile of leaves or straw.
- Rub a variety of textures on the skin like a sponge, soft cloth, feather, satin, or silk.
- Wrestle or play tickle with a friend or parent.
- Play with water "paint." Give the child a bucket of water and paintbrush and let him or her paint themselves, you, the house, or whatever they like.
- Play in the sandbox. You can build, bury, or pretend with trucks, buckets, dolls, and/or small objects. Pretend to hunt for buried treasure.
- Water play in the bathtub, sink, pool or water table. You can use a tub of water on a lap tray with toys or sponges.
- Play with and pet animals. Petting a house pet or visiting a petting zoo or pet store is fun.
- Make and play with homemade play dough.

Kinesthetic (knowing where the body is in space)

- Play mirroring games. You make a shape with your body or part of your body and the child has to mirror it. Take turns playing leader.
- Body Squeeze—Place the child in your lap and wrap yourself completely around them, giving a big bear hug. Let them give you one back and roll on the floor with them.
- Toss a big stuffed animal, pillow, or soft toy back and forth.
- Have the child create an obstacle course through the house or apartment or around the yard for both of you to go though. It can have things to go over, under, around, and/or through. You can use whatever items are laying around such as old boxes, sticks, toys, tape marks, or trash cans. Use sidewalk chalk to draw objects, paths, and patterns on cement.

Remember that any of these activities can be fun or annoying for an individual. The key is that play should be enjoyable and create an internal sense of thrill, novelty, and excitement for the child. Play and playfulness is having FUN! The less an adult structures the activity and lets the child direct it, the better. The adult is the facilitator by setting up an environment for the child to enjoy playful experiences and expression. However, it is important to have a playful, childlike attitude as you play with your child. Find and create things that are enjoyable for you and you child as you explore the magic of play. ■

Don Lytle, PhD (alias "Dr. Play"), is a Professor of Physical Education at California State University, Chico, and is former President of the Association for the Study of Play. Rebecca Lytle, PhD, is an Adapted Physical Education Specialist, and currently coordinates the Adapted Physical Activity Program at California State University, Chico.

The Lytles are married and the parents of two children.

Play dough recipes

Basic:

Mix 3 cups flour with 1/4-cup salt. Add 1-cup water with coloring and 1 Tbsp. oil gradually.

Add more water if too stiff; more flour if too sticky.

Fancy:

Mix together 2 cups flour, 1-cup salt and 1 Tbsp. cream of tartar. Add 3 Tbsp. oil, 2 cups of cold water and coloring. Mix all together.

In a pan, cook over low heat, stirring mixture until it can no longer be stirred.

Remove from the pan and knead. Cool.

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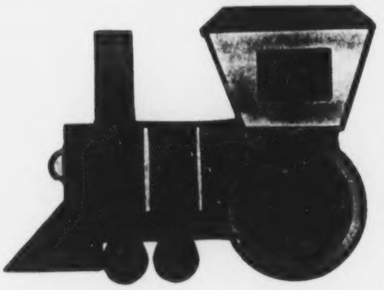
Play it **SAFE** this Season



Toy Manufacturers of America, Inc. (TMA®), the trade association of the U.S. toy industry emphasizes the importance of safe play by providing a toll-free hotline and Web site for consumers and the media, dedicated to providing the widest range of up-to-date information regarding toy safety and, new this year, the hottest toys based on U.S. sales figures.

TMA funded and launched the year-round hotline (877-4TOY-SAFETY) in 1999 to assist U.S. consumers with questions and concerns about toy safety, and to make comprehensive and accurate information available.

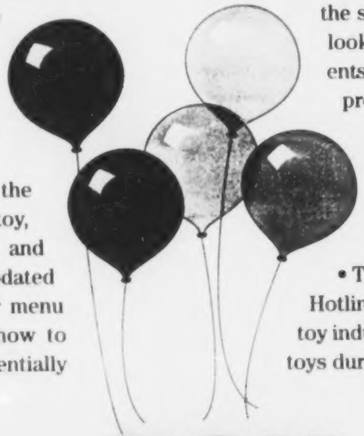
The hotline functions as a public service that allows parents and caregivers to learn about toy safety and safe play, free of charge.

The newest feature on the hotline is a list of the most popular toys, including the name of the toy, the manufacturer's name and phone number, and the suggested retail price; the list will be updated monthly based on U.S. toy sales data. Other menu options include general tips on toy safety, how to select and maintain safe toys, and lists of potentially hazardous toys publicized by other organizations. Instructions on how to order free brochures on toy safety, resources for toy safety information and toy testing criteria for manufacturers are also available.

Web site users (http://www.toyhotline.org) can use a site search function to find specific or additional information not available on the toll-free phone line. The site has a Frequently Asked Questions section that contains directions on how to access various manufacturers, as well as the National Lekotek Center, which adapts toys for special needs and maintains a nationwide toy lending center, and the U.S. Consumer Products Safety Commission. Also on the site, users can link to other sections of the site to find specific toys by name and links to manufacturers, online games, and more comprehensive information.

The TMA is determined to make this holiday season the safest ever by making important and often-overlooked safety information widely available to parents and caregivers—free of charge. These services provide an easy, accessible and positive environment for adults to obtain vital information to ensure safe play.

- Together with the U.S. government, TMA has led the world in the development of toy safety standards.
- TMA encourages parents to consult the Toy Safety Hotline number and Web site for information on the toy industry, toy safety, and parental concerns regarding toys during the holiday season and year round.



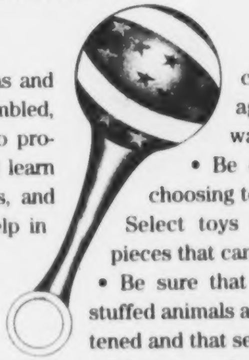
Tips for **TOY** Safety

by the Toy Manufacturers of America

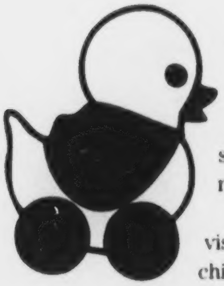
Parents are their child's first playmates. Not only do parents have an important role in choosing appropriate toys for their children, research also shows that children who play regularly with their parents enjoy the greatest developmental benefits.

Supervision of play enables the adult to read instructions and ensure that toys are being safely assembled, used, stored, and maintained. It also provides an opportunity to observe and learn more about the personality, abilities, and interests of the child, which can help in future toy selection.

Following are guidelines to ensure safe play.



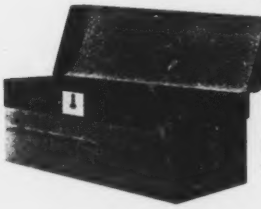
- Be sure to read labels carefully, checking for specified age ranges and safety warnings.
- Be especially careful when choosing toys for children under 3. Select toys that are free of small pieces that can be broken off.
- Be sure that the eyes and noses of stuffed animals and dolls are securely fastened and that seams are well sewn.
- Select toys that are lightweight, wash-



able, and free of sharp edges, corners, or strings.

- Choose oversized toys that cannot be swallowed.
- Closely supervise balloon use for children under 8.
- When selecting sports equipment, include protective gear.
- Avoid toys with heating elements for children under 8.
- Keep in mind that a well-balanced assortment of toys contributes to the development and pleasure of children of all ages.

Safe manufacturing and careful toy selection are not enough to protect a child. Parents and caregivers should be their own safety experts. Toys must be used, maintained, and stored correctly to ensure that the safety built in at the factory continues at home. Here are some guidelines for maintaining a safe toy environment:



- Read instructions for assembly and use. Keep product literature in case of future questions and complete and mail in warranty cards.
- Always remove and discard all packaging from a toy before giving it to a baby or small child.
- Consider the environment in which a child will play—and younger children who may be there. Keep in mind that a toy that is safe and enjoyable for an older child, may be unsuitable and potentially hazardous for a younger one.
- Supervise children when they play and set good examples of safe play.
- Remind caregivers—including grandparents—of play-related safety concerns and beware of any toys that are not played with properly.
- Choose a safe storage place for toys. If a storage chest is used, be sure that it has a removable lid or a spring-loaded support

continued on page 68

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continued from page 67

that allows the lid to remain securely open. Check for air holes to prevent suffocation and hinge-line clearances to prevent pinched fingers. Large, stackable plastic bins, smooth-edged baskets, and sturdy shelves are other good options for toy storage.

- Check toys at least every three months for damage. Make any repairs immediately or throw away damaged toys.
- Avoid leaving toys outdoors overnight. Rain, snow, and dew can cause rust and increase the risk of injuries.
- Never leave toys on stairs.

Together with the U.S. government, TMA and its members have led the world in the development of toy safety standards. A toy may go through more than 100 safety tests to imitate the kind of use and abuse it may get in the hands of a child.

The Consumer Products Safety Commission has the authority to develop and enforce safety regulations for toys and other consumer products and spends over half of its annual budget on children's items.

Manufacturers have in-house testing facilities to ensure that all products meet or exceed government standards for safety. A manufacturer producing toys overseas usually tests their toys overseas and frequently retests them once they arrive in the U.S.

Choosing toys for children with special needs

The American Toy Institute has teamed up with the National Lekotek Center, a nationwide, non-profit organization, to help make play more accessible for special children. A toll-free service staffed by play experts can recommend appropriate toys and activities for children and families.

The American Toy Institute also works with the American Foundation for the Blind, to produce the *Guide to Toys for Children who Are Blind or Visually Impaired*. For free copies, see resources box below.

Take time out to play

While supervision is critical, the richest play occurs when parents or other adults take an active role and play alongside their child. Observe your child, take his or her lead, and offer new ways to play and have fun. ■

Resources

For free information on toy use and toy safety:
visit the TMA Web site at
http://www.toy-tma.org,
and their toy safety Web site:
http://www.toyhotline.org,
or call their toll-free hotline
(877) 4TOY-SAFETY.

The National Lekotek Center
Toy Resource Helpline
(800) 366-7529.

To obtain a free copy of the Guide to Toys for Children Who Are Blind or Visually Impaired write to:
The American Toy Institute, Inc.,
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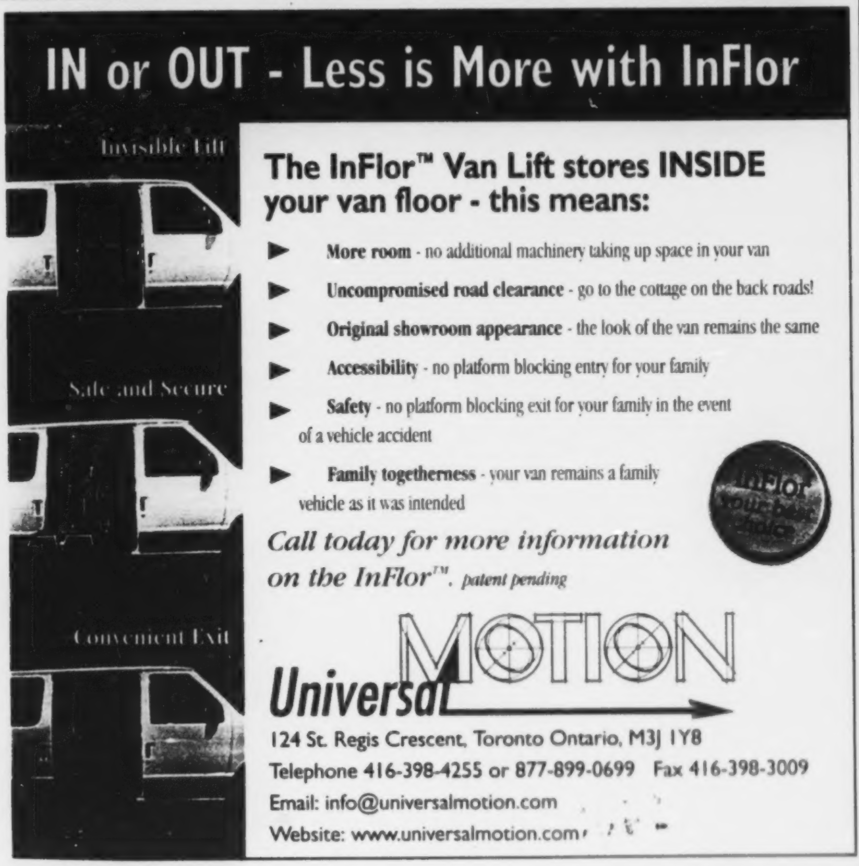
(http://www.toy-tma.org).



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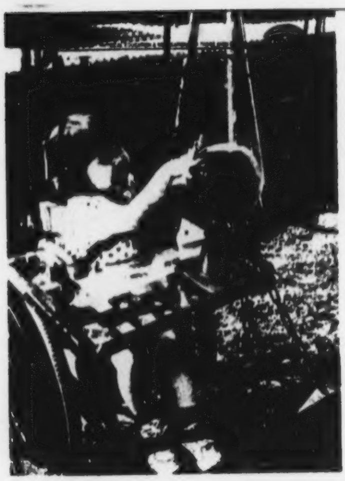

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- to increase the knowledge base of professionals working with children or adults with disabilities, making them aware of the **can do** possibilities of their students/clients;
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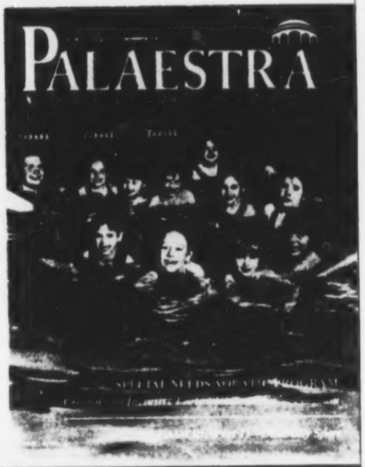

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PALAESTRA: *Forum of Sport, Physical Education & Recreation for Those with Disabilities is published in cooperation with the Adapted Physical Activity Council (APAC) of AAALF/AAHPERD and the Committee on Sports for the Disabled of the U.S. Olympic Committee.*

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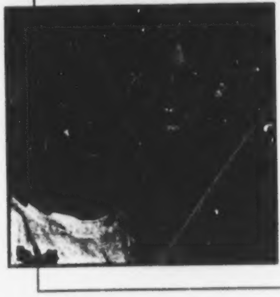
the baby einstein company presents familiar faces

MAURICA, MAURIAH & MAURICE, JR.

"The Lemon Kids" (l-r) **Maurica,**19, **Mauriah,** 9, and **Maurice Jr.,** 14, get together for a 1998 portrait. Mauriah has spastic quadriplegic cerebral palsy and G6PD deficiency, a genetic enzyme disorder. At 3 days old, she was diagnosed with jaundice, hyperbilirubinemia (an excess of bilirubin, a bile pigment, in the bloodstream), and kernicterus (the presence of a yellow pigment and lesions in the gray matter of the brain). Mauriah is nonverbal, and uses a wheelchair and a g-tube. The kids' mom, Evelyn, reports that Mauriah is always happy—even when she is having a bad day. Maurica and Maurice, Jr. enjoy taking care of their little sister. Mauriah attends elementary school, and loves playing with bubbles, water, and her younger cousins. The Lemon family lives in Huger, SC.

DANIEL & GREAT GRANDMA



Daniel Wayne Gannon, 11, and his great grandma, **Gladys Burgess**, have plenty of holiday cheer! Daniel has mild to moderate mental retardation and a severe speech/language delay. He attends Kirksie Middle School and loves to ride on the school bus. He also enjoys riding horses, swimming, and playing ball. He and his sister Melissia, 13, live in Rogers, AR, with their parents, Sandra and Denny Birdsong

DAKODA

Dakoda Jacob William Eads, 4, relaxes in front of the Christmas tree in this photo taken last year. Dakoda has hydrocephalus, a seizure disorder, hypotonia, carnitine deficiency, and developmental delays. According to his dad, Chuck, Dakoda smiles at most everyone but makes friends carefully. Dakoda attends a special education preschool and loves visiting his "Gramma" Berta. He enjoys watching his dad playing softball, and his favorite foods are Ritz crackers and french fries. Dakoda lives in Salinas, CA, with his dad, mom, Lynda, and his cat, Angel.

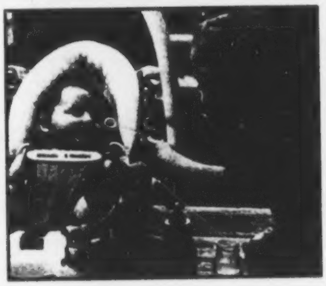
JACOB

Jacob Matthew Matuszeske, 9 months, loves to hang out with his friend Winnie the Pooh! Jacob was born six weeks premature and has Down syndrome. He attends a full-time daycare, where he enjoys playing with the other children. Jacob's favorite song is "Twinkle, Twinkle, Little Star," and his mom, Mary, describes him as a "happy, lovable little boy." Jacob lives in Fall River, WI, with his sister Corin, 19, brother Joshua, 10, mom, dad Mike, and the family dog, Molly.

BRIANNA & LEXI

Brianna Nicole, 5, (right) and **Lexis (Lexi) Rose Contini,** 3, love their dalmatians! Lexi Rose has spastic cerebral palsy, a seizure disorder, microcephaly, reflux, is fed via g-tube, and receives in-home therapy. According to her mom, Christine, she is an extremely happy little girl who loves listening to music and playing with her big sister, Brianna. Christine says that the popular song, "Heaven Must Be Missing an Angel," describes how they all feel about Lexi. The two sisters live with their mom, and dad, Johnny, in Aberdeen, NJ.

SAMMIE & RJ



Samantha (Sammie) Yost, 2, is showing her little brother **Roger John (RJ),** 6 months, how to blow bubbles! RJ was born with Rubenstein-Taybi syndrome (a rare genetic disorder associated with craniofacial abnormalities, developmental delays, and often respiratory and/or digestive difficulties). According to the children's mom, Katherine, "Sammie does her best to show RJ that he's nothing special to her, just a typical little brother. We know they are both special, and gifts that we are truly blessed to have." RJ and Sammie live with their mom and dad, John, in Pelham, NH

Would you like to share a favorite candid snapshot or slide of your child and/or family with other readers of EXCEPTIONAL PARENT? Send it to: Readers' Photos, *EXCEPTIONAL PARENT*, 555 Kinderkamack Road, Oradell, NJ 07649-1517. (Please do not send originals or "one-of-a-kinds" as we regret that **photos cannot be returned.)** On a separate sheet of paper, write your child's full name, age at the time the photo was taken, address and daytime phone number. Please identify everyone in the photo. If you like, you can also write a few sentences about your child. Then look for a familiar face in an upcoming issue!

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LEGISLATIVE UPDATE

US GOVERNMENT ENFORCING Local Compliance to ADA

by David Chamalian

In the fall of 1999, the US Justice Department launched the Project Civic Access initiative, a broad effort aimed at monitoring the extent to which cities, towns, and villages nationwide have complied with the Americans with Disabilities Act by making local modifications to public areas accessible.

Among some of the modifications:

- Improving access to public buildings, parks, and pools.
- Providing curbside or absentee balloting, or alternative polling places.
- Upgrading 911 emergency services for people with hearing impairments.
- Installing assistive listening devices in legislative chambers, courtrooms, and municipal auditoriums.
- Creating delivery systems and time frames for providing auxiliary services, including sign language interpreters and materials in Braille, large print, or on cassette tapes.

To find out if your city is due for modifications, or to read the list of other cities that have already undergone modifications, call the ADA Hotline at (800) 514-0301 (voice); (800) 514-0383 (TDD); or log on to their Web site: http://www.usdoj.gov.

Two free informational guides are also available: "Americans with Disabilities Act: A Guide for Small Towns" and "The ADA and City Governments: Common Problems." These guides review ADA requirements and offer practical examples on how to comply. They are available at the contact information above in all formats—large print, audiotape, Braille, computer disk, and automated fax-back—for people with all types of disabilities.

TELEVISION PROGRAMMING AND EMERGENCY INFORMATION MORE ACCESSIBLE FOR PEOPLE WITH VISUAL AND HEARING IMPAIRMENTS

For people with visual impairments:

Beginning in April 2002, the large national television broadcast stations and program distributors will be required to make television shows more accessible to people with visual impairments. Via the use of the Secondary Audio Programming (SAP) channel, which is available on all TV sets produced after 1990, viewers with visual impairments will be able to activate narrated descriptions of settings and actions not otherwise apparent from the dialogue in the program.

According to the Federal Communication Commission's research, an estimated 12 million people in the US have visual impairments, and it is estimated that up to 14 percent of people 75 and older have visual disabilities. The Commission said that video description may benefit secondary audiences of up to one and a half million children, ages 6 through 14, with learning disabilities by "capturing their attention and enhancing their information-processing skills.

Emergency information

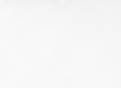
The FCC has also made it mandatory for all broadcasting stations that provide local emergency information to make the critical details of such information accessible to people with visual disabilities. Prior to delivering the emergency information, stations will be required to sound an aural tone, which will alert people with visual disabilities that information is forthcoming.

For people with hearing impairments:

Recognizing the growing prevalence of digital TV, the FCC has required that by July 1, 2002, digital television receivers must come equipped from the manufacturer with "compliant DTV closed-captioning decoder circuitry."

Provisions of the new rule will also allow viewers to choose and modify the color, size, and font of the captioning and choose between multiple streams of captioning, such as "easy reader" or alternate language captioning. ■

For more information on any of the new rules above, call the FCC consumer information line at (888) CALL FCC (225-5322) (voice), or (888) TELL FCC (835-5322) (TDD); E-mail: fccinfo@fcc.gov; Web site: http://www.fcc.gov; or write: FCC Consumer Information, 445 12th St. SW, Washington, DC 20554.



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Circle #41

organizational spotlight

The Marcus Institute

Partnering with the Kennedy Krieger Institute brings services to underserved children.

Grounded in more than 65 years' experience serving children and adolescents with neurological disabilities, Baltimore-based Kennedy Krieger Institute (KKI) is renowned for its expertise—not only in providing care but also in research, professional training and education related to childhood disabilities. Through its commitment to sharing its acquired wealth of knowledge in the field of disabilities, KKI has enjoyed an informal affiliation with the Atlanta-based Marcus Institute since its inception in 1992. A generous donation from Bernard Marcus—the entrepreneur behind Home Depot who is also a philanthropist and co-founder (with his wife Billie) of the Institute—enabled a formal partnership in 1998.

Marcus Institute

An affiliate of Kennedy Krieger Institute at Emory University

As a result of this merger, the Marcus Institute has become the cornerstone of a long-range plan envisioned by KKI to establish a national network of developmental behavioral services for children with neurological disorders and to heighten awareness regarding disabilities within communities and legislative systems governing them. Says Marcus, "We want to take the very best of what's happened in Baltimore and move it to Atlanta, then to other cities."

Highly specialized programs offered at the Marcus Institute require equally specialized medical professionals. Bernard Marcus, (r.) the co-founder of the Marcus Institute visits with one of the children at the Institute.

Prior to the establishment of the Marcus Institute, children with developmental disabilities living in the Southeast region of the US were diagnosed and treated somewhat inconsistently. Moreover, coordination of services among providers, critical when managing complex disabilities requiring various specialists and services, was often disjointed. The Marcus Institute fills an important void by offering coordinated and appropriate services for children whose needs were not previously met.

Highly specialized programs offered at the Marcus Institute require equally specialized medical professionals. Some of these programs, such as the Behavior Center and the Pediatric Feeding Disorders Program, utilize techniques that have been proven effective through years of application and refinement at Kennedy Krieger Institute.

Addressing severe behavioral disorders

For the children who live with this problem—approximately 10-15 percent of individuals with mental retardation, autism, or severe developmental disabilities—not a lot of options exist. Families may turn to pharmacological therapies, which have produced mixed results at best. From sheer desperation, families sometimes consider placing such children in institutions. Out of this dire need grew Kennedy Krieger Institute's neurobehavioral inpatient and outpatient programs in Baltimore and now, an affiliated program at the Marcus Institute in Atlanta.

The goal of these programs is to provide advanced and comprehensive treatment services, promote widespread dissemination of effective treatment technologies through highly specialized training and consultation, and facilitate the development and refinement of effective treatments through systematic evaluation of clinical innovations.

Positive results are evidence of behavioral theories that can work as well in practice as they read in text books, when applied with meticulous detail and consistency. Not only have the behavior analysis techniques honed by the NBU staff proven effective in treating the most difficult behavioral problems—the staff achieves a 90 percent decrease in aggressive behavior among three quarters of its inpatients and a recidivism rate below 5 percent—they have set the standard for the entire country.

Keeping families together

Scott Fendlay was born with his umbilical cord wrapped around his neck. Despite the pessimistic predictions of medical professionals who told the Fendlays that Scott would never walk, he learned to walk, ride a bike, and roller-skate. But as Scott got older, his behavior began to present a major challenge to his family. "Scott's behavior worsened to where he was a threat to our safety,"

The Neurobehavioral Unit's goal is to provide advanced and comprehensive treatment programs.

says Scott's mother Carol. He was a big adolescent strong enough to heave the microwave oven out the window and cause injuries to his parents. "At that point, life was just…impossible," says Carol.

Then Carol learned about Kennedy Krieger's Neurobehavioral Unit (NBU) and eventually, Scott was admitted to the NBU as an inpatient, where he stayed for two months.

From the beginning, the Fendlays let Dr. Wayne Fisher, who was then the director of the NBU in Baltimore and now heads its sister program in Atlanta, know that their main priority was to get Scott's behaviors manageable enough to where he could return home. Dr. Fisher not only respected their wishes, he exceeded them. "I have called him [Dr. Fisher] many times and he's even come to my house when things were really, really bad with Scott, and we've reasoned with him," Carol notes.

Scott is now 32 years old. Every weekday, he chooses to dress in a tie and pressed shirt before boarding a bus that takes him to an adult day care center. In his free time he enjoys bowling in a recreational league and listening to music on his walkman.

Keeping Scott's behaviors in check remains an issue. A "token" system, developed jointly by Carol and Dr. Fisher while

continued on page 76

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Circle #29

continued from page 75

Scott was on the NBU, helps to make this challenge manageable. "I find that you have to use the protocol every day. Not just Monday, or Friday," says Carol.

Scott's progress can be attributed largely to his family's decision to treat him like a healthy, contributing member of the family. "Overall, he's given us much more back than we've ever had to give out," remarks Carol. Explains Wayne Fisher, Ph.D., "Bernie Marcus gave us his donation because he realized how important these behavior problems are, how devastating they are to families, and how little attention and financial resources have been devoted to them." And it is these specific challenges that are driving the continued evolution of the Kennedy Krieger and Marcus behavioral programs.

The Pediatric Feeding Disorders program is designed to help children who are failing to consume the appropriate amount of nourishment to survive because of medical or behavioral dysfunction.

When children won't eat

Another service that sets Kennedy Krieger and Marcus Institutes apart is the Pediatric Feeding Disorders program.

Designed to help children who are failing to consume the appropriate amount of nourishment to survive because of medical or behavioral dysfunction, this program combines the medical expertise of pediatric gastroenterology and the precise therapeutic interventions of behavioral psychology to evaluate and treat children with feeding impairments.

The program is unique because of its intensity and interdisciplinary nature, and this is the reason that families travel from all over the country, and sometimes the world, to enroll their children. Most of the children who are seen in this program have been through many other attempts to get them to eat, including—when nothing else works—inserting a feeding tube via the nasal passage or gastrointestinal tract.

The practice of meticulously analyzing data and recording observations has made professionals in Kennedy Krieger and Marcus' Feeding Disorders Program experts in behavior analysis. It has also contributed to the staff's numerous published studies proving the benefits of this methodology.

Before admission to the feeding program, Leslie Muldrow constantly worried about her daughter's weight. After Aylea's enrollment in the program, she ate a variety of foods that, before, she never would have even swallowed. But Aylea's follow-up visit

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Circle #32

> **While the tools and techniques used to treat children with disabilities have changed and improved significantly over the past 60 years, the guiding focus on comprehensive, interdisciplinary, and individualized care remains at the core of these two Institute's philosophy.**

after discharge was to be the true test for her mother. Then she would know how effectively she had assisted Aylea with maintaining the progress she made while in the program. The fateful day came two months after Aylea's discharge. When Aylea hopped on the scale, it read two pounds more than what she weighed at discharge.

"Follow-up is such an important part of the long term outcomes for our patients," explains Dr. Cathleen Piazza, behavior psychologist and director of the Pediatric Feeding Disorders Program at Kennedy Krieger and Marcus Institutes. This continued involvement with patients and their families has helped keep the program's recidivism rate below 5 percent, and was in part the impetus for piloting a telemedicine component within the program.

Currently, Kennedy Krieger and Marcus' feeding experts consult via teleconferencing between program locations in Baltimore and Atlanta, allowing staff to collaborate on individual cases. And, in homes in both markets, patients and their families have been connected to the Institutes' experts through teleconferencing capabilities, working virtually with therapists during feeding sessions and follow-up consultations.

"The demand for these services is so great, we needed a way to expand our Feeding Disorders Program capabilities and to reach families who were unable to travel to Atlanta or Baltimore," explains Cathleen Piazza Ph.D. "This new approach enables us to help more children and their families, right in their home environment."

An educational and research focus

Kennedy Krieger Institute shares an educational and research affiliation with The Johns Hopkins University School of Medicine in Baltimore, and Marcus Institute shares a similar relationship with Emory University School of Medicine in Atlanta.

Faculty at both facilities conduct professional training and research to discover preventions and novel therapies for disorders of the brain that begin in childhood. Together with families, support groups, government agencies and foundations, the Institutes advocate at the local, state and national levels for fuller integration of individuals with developmental disabilities into school and community life, better access for families to appropriate clinical and educational services, and enhanced funding for research and training in this field.

While the tools and techniques used to treat children with disabilities have changed and improved significantly over the past 60 years, the guiding focus on comprehensive, interdisciplinary and individualized care remains at the core of these two Institute's philosophy.

"Ultimately, in everything we do—whether it be a new therapy to help children with lead poisoning learn better, microarray research to uncover the genetic cause of autism, or training with a new group of pediatric neurologists—we strive for one common goal, to improve the lives of children with disabilities and to help them participate as fully as possible at home, school and in their community," summarizes Gary W. Goldstein, president and CEO of Kennedy Krieger Institute. ■

To learn more, please visit Kennedy Krieger Institute's Web site at http://www.kennedykrieger.org or Marcus Institute's Web site at http://www.marcus.org, or call 1-888-554-2080.

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Circle #18

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Ask the Therapist

Answering Questions About Pediatric Braces and Strapping Systems

by Ginny Paleg, MS, PT

Q Dear Ginny:

My 11-year-old daughter, Amanda, has severe spastic quadriplegic cerebral palsy and periventricular leukomalacia. She is fed via g-tube and uses a communicator. She is completely non-ambulatory and weighs about 70 lbs. She can bear some weight on her feet but needs a lot of assistance. She is working on helping with transfers. Her steps would be on her tip toes if she did not have her ankle-foot orthotics(AFOs, braces for the foot) on and if I wasn't supporting her under her arms. I only make Amanda wear her AFOs at school. She doesn't like them, I'm probably too much of a softy for her own good.

How important is it to use the Velcro® toe strap that wraps around the big toe on the AFO? It looks so uncomfortable that I frequently don't use it, but the therapist seems to feel it is a critical part of the orthotic. She does not curl up her toes without the toe strap on the AFOs (in my opinion). I think her foot just tries to point inward a little bit. Why stick a piece of Velcro between your toes when you have winter socks on? What's the point? Thanks for your insight.

Francie - mom to Amanda and Christine, 22, a graduate student.

A Dear Francie:

I had these same questions not so long ago. It seemed like every professional I met had a different term and opinion for the different braces, strapping systems, and even the materials used. Since your letter, I've done some investigating and spoken to some experts (Beverly Cusick, PT, Sue Uglietta, MPT, and Cascade DAFO, Inc.)

Most therapists and orthotists agree that the key to an excellent orthotic is the footplate and the cast. The footplate is what gives the bottom of the brace its contour and shape. If the bottom of the brace (the inside part where the bottom of the foot sits) is flat, the wearer will not get optimal control of the foot.

The footplate also supports the structure of the rest of the AFO and is made just prior to casting. Some orthotists and therapists will make AFOs on the specifications of the physician using pre-made foot plates, and others customize. The footplate adds the "bumps" and support in just the right places. Bumps under the arch and/or under the metatarsal heads (where the toes connect to the foot) help support the bones so that the muscles, ligaments, and tendons are in an optimal position and ready to work. After the footplate is fabricated, then it is time to make the cast for the AFO. The footplate is placed on the bottom of the user's foot and is incorporated into the cast.

In answer to your question about the need for a toe strap, it could be that a good footplate might be the answer. The footplate would decrease pronation (flatfeet or fallen arches) and decrease forefoot compensations (in your daughter's case, toe pointing inward) and the need for a toe strap.

Look inside your daughter's brace and then at your daughter's foot. See if it looks like the foot is supported well, or allowed to collapse. If you want to get rid of the toe strap, you may want to try a new AFO that is made from a cast with a good footplate.

The key to a good brace is that it keeps the foot supported and in the right place (biomechanical alignment). The foot is perpendicular to the leg with the heel (subtalar neutral), midfoot and forefoot all maintained as straight as possible. When the foot is kept in biomechanical alignment, it may prevent deformity, keep the muscle in the best position for movement and improve your daughter's ability to stand, transfer, or take steps in a gait trainer. Most therapists believe that maintaining bones and limbs in biomechanical alignment leads to better quality of movement, less muscle contractures, and less joint pain as the person ages.

The right kind of brace is important. Too little or too much support can lead to sub-optimal walking. Here's a simple guide to the kinds of orthotics I usually recommend. There are other types that have been developed or adapted, but these are the types most commonly used.

I hope this explanation and chart helps you understand the reasons for using foot braces and the wide range of choices available.

This month's guest columnist, Ginny Paleg, MS, PT, is a pediatric physical therapist at the Hospital for Sick Children in Washington, DC. She can be reached by phone at (800) 226-4444, or via e-mail at gpaleg@hospsc.org.

Ask the Doctor addresses issues of concern to our readers and is usually coordinated on a monthly basis by David Hirsch, M.D., a pediatrician and member of EXCEPTIONAL PARENT's Editorial Advisory Board. Dr. Hirsch is a partner in Phoenix Pediatrics, Ltd., in Phoenix, Arizona, and specializes in treating children who have developmental disabilities and chronic illnesses. Parents should review any suggestions made in this column with the appropriate professionals. Mention of specific products or medications illustrate suggestions and are not endorsements of Any specific products. Send questions to: Ask the Doctor, EXCEPTIONAL PARENT, 555 Kinderkamack Road, Oradell, NJ 07649-1517, or fax, (201) 634-6570.

Types of Ankle Foot Orthotics

Rigid AFO (with toe strap)

A solid ankle brace provides excellent foot and ankle control for children with severe spasticity, but does not allow any ankle movement. If my client cannot walk at all, but is in a stander and/or assists with transfers, this is the brace I choose. Some orthotists use this type for children who walk and have a lot of extensor tone (too much pushing from the ankle) or for children who collapse forward over the ankle (crouch gait).

Dynamic AFO

Shorter than a traditional AFO, dynamic AFOs provide dorsiflexion assistance (help in turning the foot or toes upward) for children with hypotonia (low muscle tone) and/or weakness. This brace will not resist strong plantarflexion (walking on the toes). High side support on the foot keeps the foot in good position during standing and the part of gait when the leg is fully weight bearing (stance phase). Mild spring provides more consistent toe pickup, but does not block normal ankle motion during gait. The special part or "trick" about this brace is that there is no tibial strap. This allows the lower leg to move forward over the foot (dorsiflexion)

Articulated AFO

This type of brace has a hinge at the ankle, which allows free dorsiflexion (toe part of the foot comes up) but limited plantarflexion (toe part of the foot goes down). This encourages a more normal gait pattern in children who have at least 5° of dorsiflexion range of motion at the ankle. The hinge can also be adjusted to limit the amount of dorsiflexion.

Floor reaction AFO

This AFO is solid in the front. The child puts on this brace by slipping the foot in from the back of the brace. The design of this brace forces the knee into extension when the foot is flat on the ground. It is specifically for children with a "crouch gait" (too much knee bending) because of hamstring spasticity or quadriceps weakness. To successfully use this brace, the child must have full range of motion at the knee.

Supramalleolar ankle foot orthosis (SMO)

SMOs cover the bottom of the foot and extend up to just below the ankle. They are used to help control ankle pronation (eversion, or rolling in) and hindfoot valgus (rolling out) position. It is often used in children with mild to moderate spasticity who are just beginning to walk.

Dynamic splint/stretching AFO

Dynamic splinting provides an adjustable springloaded tension. This "push" gives a low dynamic stretch to the muscle, which can help increase range of motion. It is also effective as a nighttime splint to increase ankle range of motion.

Inserts, Arches, Cookies, etc

These minimally supportive options provide foot control for a child with hypotonia (low muscle tone) who is walking and/or standing. These braces may also work for a child with mild diplegia or hemiplegia who has slightly high muscle tone and/or a mild flat foot (minimal biomechanical issues). They work as a compromise for children who do not want to wear their AFOs regularly, or for special occasions when a child wants to wear fancy shoes that cannot accommodate a bigger brace. ■

Images provided by Cascade DAFO, Inc. (800) 848-7332.

In Search of Lemonade

by Diane McAuley

"When life gives you lemons, make lemonade!" Yes, it is a corny expression, but one I have always tried to live by. While it can apply to any aspect of my life, it is particularly significant with regards to my daughter. Her name is Megan and she has cerebral palsy. I just picked up her new pair of splints at the orthotist's office. We have had several pairs in the past. We have had AFOs (ankle-foot orthotics) up to the knee, in white and pink. We have had flesh-toned SMOs (supramalleolar orthotics) ankle-height, which were hardly visible above her shoes or sneakers. She never liked any of them, but she had to wear them for her own good, and I made sure she did.

Diane McAuley and her daughter, Megan, always look for the good in life's challenges.

This new pair is different. They are huge. They have moving parts with bolts. There is a long piece of Velcro® that goes down the back and can be tightened, not unlike using "the rack." It comes with its own Allen wrench, which fits into a part that juts out of the back.

They are so ugly, not even a mother could love them.

I asked the orthotist what kind of "Bozo" shoes I was going to have to get to fit over these monstrosities. He assured me that I could find sneakers that would not be too much bigger than her normal size. Well, he was wrong. Megan wears a size $1^{1/2}$ shoe and the smallest thing I could get to go over those beauties is a size 5. And they are not pretty.

When I was pregnant, I wanted a daughter so that I could give her pierced ears and braid her hair and paint her nails. I wanted to dress her in cute little outfits with matching accessories. After four years of dressing my son in blue pants and striped shirts, I needed something frilly and feminine! At my baby shower, a co-worker gave me a little pair of pale blue corduroy shoes with tiny pink flowers on them. They came in a clear plastic package, and I loved looking at them. This is what having a baby girl was all about.

When Megan was born we did not know that she had CP, but she did have a club foot. At five days old, her right foot was put in a cast, and at three weeks, she went directly into orthopedic shoes with a bar that connected the two feet. Months later she went into regular orthopedic shoes, which had to be replaced every month or two. They came

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in one style: white high tops and unattractive. The little blue corduroy shoes with the pink flowers were put away unopened, forever.

But I believe in making lemonade and looking for the good in all situations, so instead of shoes I concentrated on socks. Megan must have had a thousand pairs of socks! They came in all colors. They were sporty. They were dressy. They were cotton. They were lace. There was a pair to match every outfit and every occasion. And they got me through the orthopedic shoe phase.

I am having trouble coming up with something positive about this new pair of splints. Her pants do not fit over them. With those sneakers, how can she wear a dress to her fifth grade graduation? They will be hot in the summer and she will beg not to wear them. I cannot blame her. Technology has allowed us to disguise so many other imperfections: invisible braces for teeth, tiny hearing aids, contact lenses. So why hasn't someone invented something more attractive for the legs?

Megan today, with her dog, Cody, and an assortment of the splints and braces she has worn over the years.

I know that many of you are reading this and saying, "What are you complaining about? At least your kid walks." I am trying very hard to concentrate on the fact that Megan is healthy and pretty and very precious to me, because those are the things that matter most. It is a consolation. But it is not lemonade yet. ■

Diane McAuley is a Special Education Teacher and works for the New York City Board of Education. Today, Megan McAuley is an 8th grader at Ardsley Middle School in Ardsley, NY. In the past year, she has had three surgeries on her foot, and will (hopefully!) no longer need splints. Megan lives in Hartsdale, NY, with her mom, dad Hugh, and brother, Matt, 18.

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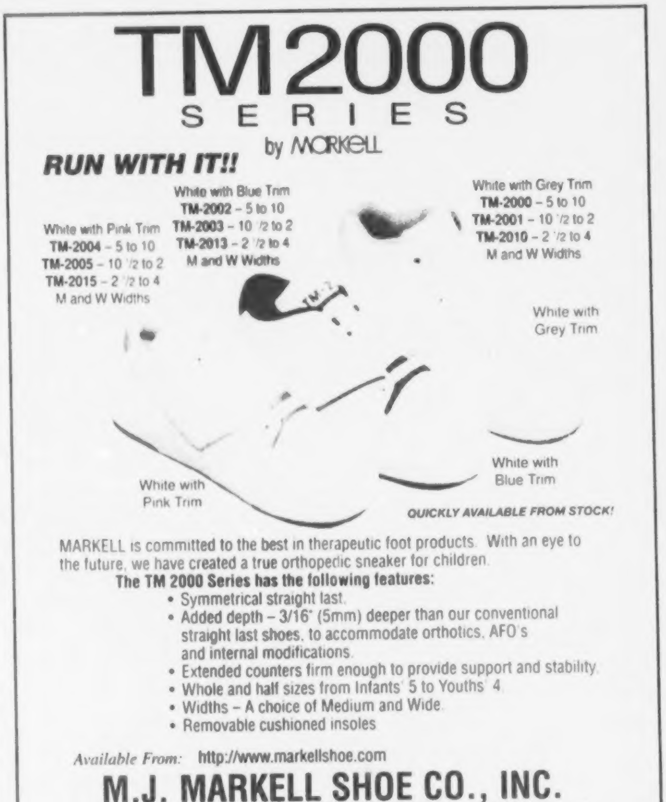

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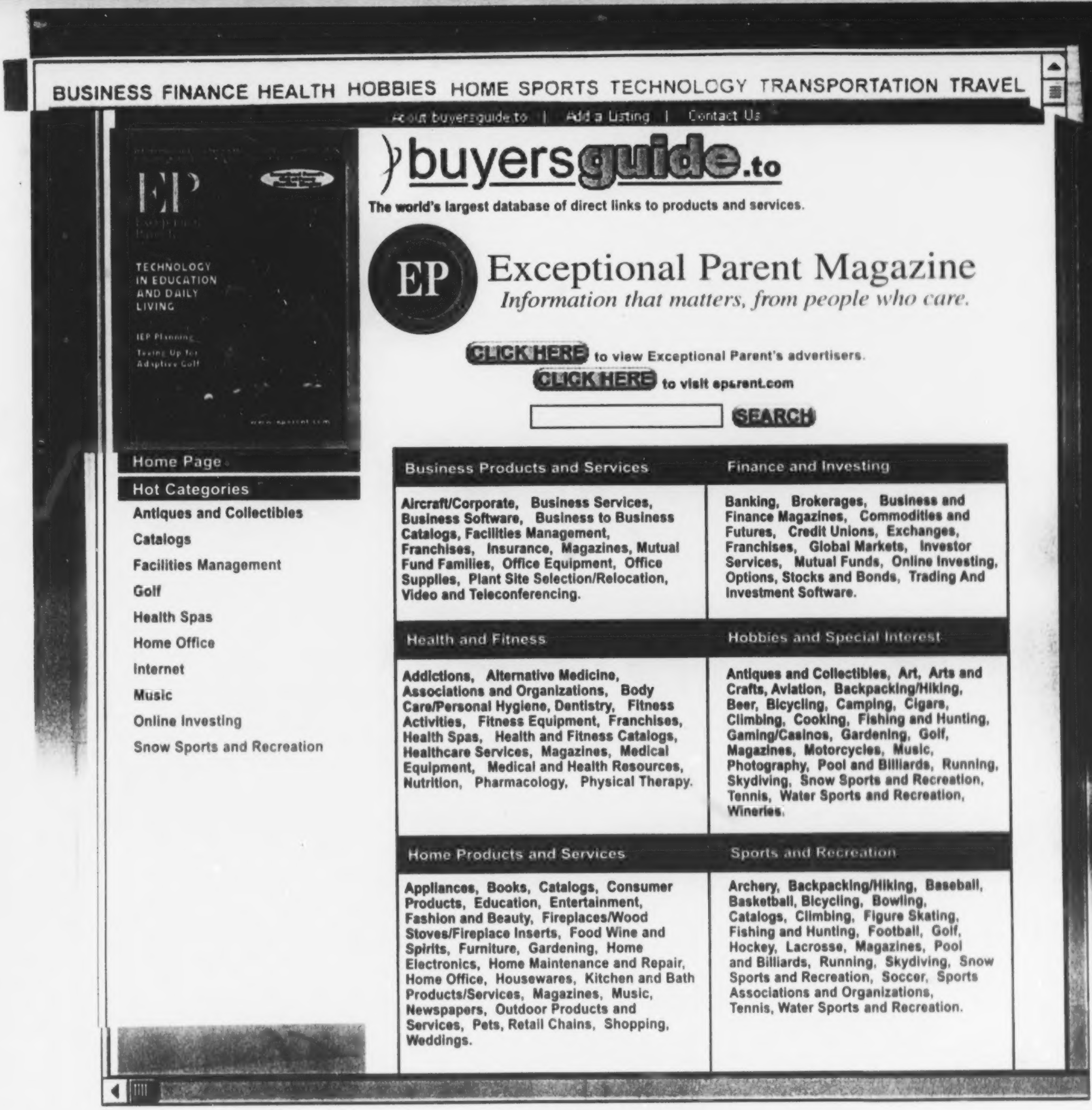
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TEMPLE GRANDIN WITH FOREWORD BY OLIVER SACKS
The author is a gifted animal scientist who has designed one third of all the livestock-handling facilities in the US. She is also autistic, a woman who thinks, feels, and experiences the world in ways that are incomprehensible to the rest of us. In this unprecedented book, the author delivers a report from the country of autism. Writing from the dual perspectives of a scientist and an autistic person, we learn how the country is experienced by its inhabitants and how she managed to breach its boundaries to function in the outside world. What emerges is a document that sheds light on the riddle of our common identity.
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KEYS TO PARENTING THE CHILD WITH AUTISM NEW!
MARLENE TARG BRILL, M. ED.
An explanation of what autism is and how it is diagnosed. You get advice on identifying resources, working with the therapeutic community, as well as helping a child with autism develop to their potential.
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This methods book for teachers and parents describes a complete program of developmental therapy for young children with autistic characteristics.
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A Helpful Guide for Parents of the Physically Disabled NEW!
CHARLOTTE E. THOMPSON, MD
This powerful and significant book goes well beyond the promise of its subtitle; far more than a "helpful guide," it could well serve initially as a primer for survival for parents new to the arena of disabilities or chronic illness, and a problem-solving helper as time goes on.
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M. HANSON & S. HARRIS
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How to establish relationships that will support you child after you're gone
LINDA J. STENGLE
Practical advice designed to guide parents through the human side of planning for their child's future. Step by step process to establish a network of non-paid people that can provide lasting relationships for the child. Emphasis on early planning.
WB174OO **$37.50**

EXTRAORDINARY KIDS
Nurturing and Championing Your Child With Special Needs NEW!
JONI EARECKSON TADA
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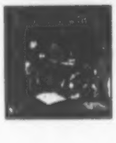

ALL ABOUT ASTHMA
WILLIAM AND VIVIAN OSTROW
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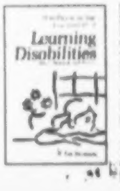

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Theory, Research and Practice
H. LEE SWANSON NEW!
An exploration of the theories and research that are the underpinnings of the assessment process. Focuses on the assessment of cognitive, language, behavioral, and academic skills.
PE154LD **$37.00**

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PAUL J. GERBER AND DALE S. BROWN
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ABC FOR YOU AND ME NEW!
MEG GIRNIS, PHOTOGRAPHY BY SHIRLEY LEAMON GREEN
A creative way to teach the alphabet to any youngster. It has a fun and exciting word to learn for every letter of the alphabet.
AW101BYP **$14.95**

THE SURVIVAL GUIDE FOR TEENAGERS WITH LD NEW!
RHODA CUMMINGS AND GARY FISHER
A step by step handbook of school skills and life schools designed to answer your questions about succeeding in school and preparing for life as an adult. Age 13 and up.
FS200LD **$11.95**

FOR YOUNG PEOPLE

WE CAN DO IT! NEW!
Five small children, each with a disability, tell all that they are able to do. Each has a restrictive condition but manages to have a full and rewarding childhood.
CH094GN English **$13.95**
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PATRICIA A. DAVIS, ILLUSTRATIONS BY LAYNE JOHNSON
A heartwarming tale of a young blind boy and the joys he finds through his friendship with a bird, his new pair of eyes.
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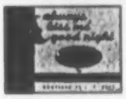

ALWAYS KISS ME GOOD NIGHT
Instructions on raising the perfect parent
Instruction on raising the perfect parent, as seen through the eyes of 147 children.
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Directories of National Organizations, Associations, Products & Services
Our largest and most valuable reference tool for parents and professionals. Includes comprehensive listing of resources for specific disabilities; guide to accessibility in theme and amusement parks; directory of managed care organizations, adaptive sports and recreation organizations, Universities and Colleges with programs for student's with learning disabilities and much more.
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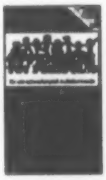

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The only independent guide to children's media, this book takes the guesswork out of finding the best products for kids from infancy to age ten (10). Here are over 1,000 expert and kid-tested products that are sure to entertain as well as educate. Included are safety tips and a Basic Gear checklist for the best new and classic products your kids will love. Brand name comparisons are included
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One of the most comprehensive references on infant mental health. Each up-to-date chapter offers a concise account of the state of the art, providing a wonderful testimony to the progress that has been made in the area.

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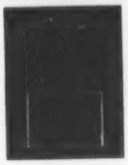


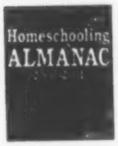
INCLUDING STUDENTS WITH SPECIAL NEEDS

A Practical Guide For Classroom Teachers **NEW!**

MARILYN FRIEND AND WILLIAM D. BURSUCK

This essential guide to teaching students of all ages with disabilities is a must read for every educator, and administrator. It provides real life examples, clear definitions of terms and laws, and even illustrates some classroom activities that make inclusion and learning both fun and easy.

PK200SE **$59.00**



HOMESCHOOLING ALMANAC 2000-2001

MARY AND MICHAEL LEPPERT

A unique compendium of resources and techniques to effectively teach using the homeschooling method. It is an easy to use and easy to understand guide that puts the emphasis on the intrinsic joy of learning.

PR1475E **NEW!** **$24.95**

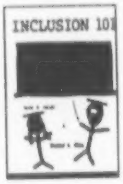
C.O.A.C.H.

Choosing Outcomes and Accommodations for Children A Guide to Educational Planning for Students with Disabilities

MICHAEL F. GIANGRECO, CHIGEE J. CLONINGER **NEW!**

This user friendly popular planning tool provides detailed explanations, explicit instructions, "helpful hints" for each step, and tabs for pinpointing information. It contains established, practical, and field tested methods for both special and general educators, relayed service providers, school administrators, and parents who work toward creating a meaningful IEP for each students.

PB3238ED **$37.95**



INCLUSION 101

How to Teach All Learners **NEW!**

ANNE M. BAUER, EDD. AND THOMAS M. SHEA, EDD.

In each classroom there are students who vary significantly from their peers in terms of interactions and learning styles. According to the authors, this essentially makes every classroom an inclusive one, regardless of design. This book illustrates how teachers can assess classroom environments and situations, develop and implement effective inclusion strategies, promote active participation, and do much much more.

PB3726IN **$35.00**

FLYING BY THE SEAT OF YOUR PANTS

More Absurdities and Realities of Special Education

Michael F. Giangreco **NEW!**

Contains more than 100 cartoons that are humorous, enjoyable, and a resource for educators, parents, and advocates Designed to encourage better educational practices by considering various absurdities of some current practices; stimulate readers to think differently; provide a tool for readers to use in their quest to improve education for children.

PP400ED **$21.95**

BILINGUALISM AND SPECIAL EDUCATION

Issues in Assessment and Pedagogy **NEW!**

JIM CUMMINS

This valuable data-based work should be read by everyone involved in special education. It raises a number of important and timely questions about diagnostic methods and tests as well as appropriate classroom structure and curricula.

PE130SE **$31.00**

MENTAL RETARDATION

YES! SHE KNOWS SHE'S HERE

NICOLA SCHAEFER **NEW!**

A fascinating story of the life of Catherine, a woman born with severe mental retardation, and her move from her parents' house into her own home. Celebrating the 10th anniversary of her move, Cath shares the excitement and success of her efforts.

IP100MR **$15.00**

RETARDED ISN'T STUPID, MOM!

SANDRA Z. KAUFMAN **NEW!**

At 2 She was labeled Mentally Retarded, at 22 she was living on her own...a fast paced engaging story where the mother of a two year old mentally retarded child reveals her feelings of denial, guilt, frustration, eventual acceptance, and the resulting determination to help her child live an independent life. Every accomplishment of the child brings hope, and every outcome teaches others about setting expectations.

PB3785MR **$22.95**

ATTENTION DEFICIT

ADHD HANDBOOK FOR FAMILIES

A Guide to Communicating With Professionals **NEW!**

PAUL L. WEINGARTNER

This empowering book gives families practical concrete know how. It illustrates how to develop behavior modification plans, decide about medication, and how to work with clinical and education professionals for effective interventions.

CW173AD **$20.95**

ADHD IN ADOLESCENTS

Diagnosis and Treatment

ARTHUR L. ROBIN

An excellent resource for both therapists and educators. It balances both the medical and psychological aspects of treatment in readable down to earth manner. It addresses the important characteristics of adolescents that affect those in that age group's acceptance of treatment. It helps formulate effective assessment and goals that teenagers and their parents are comfortable with and can also comprehend.

GL113AD **$24.95**

PARENTING A CHILD WITH ATTENTION DEFICIT HYPERACTIVITY DISORDER

JANE N. HANNAH

A practical and easy to read book that offers proven parenting approaches for helping children with ADHD improve their behavior. **NEW!**

PE167AD **$29.00**

ATTENTION DEFICIT/HYPERACTIVITY DISORDER IN THE CLASSROOM

A Practical Guide for Teachers

DOWDY, PATTON, SMITH, AND POLLOWAY

A complete guide on how to deal effectively with students who have attention deficits in their classroom

PE149AD **NEW!** **$29.00**

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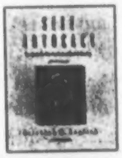

SELF ADVOCACY FOR STUDENTS WHO ARE DEAF OR HARD OF HEARING

KRISTINA M. ENGLISH **NEW!**

A selection of lessons designed to help deaf students capitalize on the positive effects of peer group interactions when the "safety net" of special education is removed.

PE163HI **$29.00**

THE YOUNG DEAF CHILD

DAVID M. LUTERMAN, ELLEN KURTZER-WHITE, AND RICHARD C. SEEWALD

A fascinating review of the historic treatment of deaf children, and an outline of what has been proven to be best for the child, early intervention, maximization of technology, and strong family involvement. A must have for all who live with someone who is deaf.

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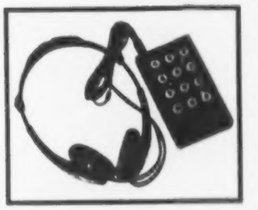

THE ROAD RUNNER TALKING BIBLE

This portable, hand-held, text-to-speech player provides the listener with easy access to the entire text of the bible. Although it was designed for people with visual disabilities, the Bible can be enjoyed by anyone who would prefer to hear the text rather than read it. It weighs 4 oz. and plays continuously for up to 40 hours on two AA batteries. The telephone-like keypad enables the user to skip from one verse, chapter, or book to another and bookmark favorite passages. The user can adjust the volume and reading speed, as well as the voice type.

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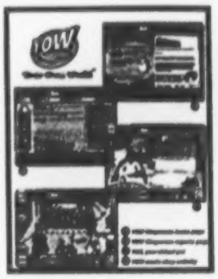
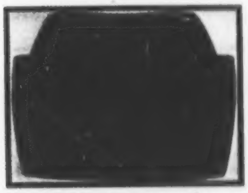


YOUR OWN WORLD (YOW)

This is a new software program that provides completely controlled Internet access for children ages 2 through 12. Constant supervision becomes unnecessary because the child is not actually online. Such a controlled method of access to the Internet can benefit some children with learning disabilities because it minimizes certain frustrating elements, such as too many options and long waits for downloads and pageloads. The parent can load the software and select the Web sites the child may visit. Once the software is on the computer, the child can choose from these sites and experience all their content, such as learning activities, games, animation, etc., without having to log onto the Internet. In addition, the faster time for downloading and transitions lessen the opportunity for distractions.

Passport New Media, 12211 W. Washington Blvd., Los Angeles, CA 90066; Phone: (310) 915-0060;
Web site: http://www.yourownworld.com



ALPHASMART 3000

This small, portable computer companion allows a child to enter and edit text anywhere, and send it to any computer (PC or Macintosh) for formatting or directly to a printer. Two-way transfers allow for downloads of any text, such as homework assignments, quizzes, or e-mails. The AlphaSmart 3000 also enables the user to cut, paste, or copy within and between files and has enough memory to hold about 100 pages of text. Other features include a spell checker, password protection, foreign language support, keyword search and special needs functions such as sticky keys, and key repeat control.

AlphaSmart, Inc., 20400 Stevens Creek Blvd., Ste. 300, Cupertino, CA 95014; (888) 274-0680; (408) 252-9400; Web site: http://www.alphasmart.com

THE SOAP SWING

The soap swing is a soft nylon mesh bag with a long handle that attaches to the shower wall and keeps the soap within reach. This eliminates the risks associated with fumbling, reaching, and bending over for dropped soap. The bar of soap will never drop, nor will it fall to the shower floor. The bag lathers quickly and easily encourages exfoliation like a sponge. The soap swing can be mounted to tile or plastic showers and baths with the included self-adhesive Velcro® strip.

TSK Products, 12 Windsor Dr., Eatontown, NJ 07724; (732) 389-5061; Web page: http://www.dynamic-living.com; E-mail: soapswing@aol.com

LITTLE SMART SUPER SMARTY

An engaging switch-operated toy for children ages 3 to 6 years with upper-extremity or cognitive disabilities, Little Smart Super Smarty looks like a robot and uses 12 double-sided activity cards to review letters, numbers, spelling, simple math, shapes, matching, colors, and more. The Liquid Crystal Display gives clear, simple directions, and shows fun animations. Ten LED lights mark the question being asked and the correct answer. Smarty's eyes light up and an encouraging phrase is played after each correct answer. Play is also enhanced by five built-in tunes.

Turning Point Therapy & Technology, Inc., PO Box 310751, New Braunfels, TX 78131-0751; Phone: (877) 608-9812; Web site: http://www.turningpointtechnology.com

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The ABLEDATA database of assistive technology and rehabilitation equipment contains information on more than 25,000 products for persons of all ages who have a physical, cognitive, or sensory disability. Products are chosen for this page by the ABLEDATA staff based on their specific applicability to or design for children who have disabilities. ABLEDATA, operated by Macro International Inc., is funded by the National Institute on Disability and Rehabilitation Research under contract number HN-96015001.

For more information on these and other assistive devices, or to submit product information for the database (and possible inclusion on this page), contact: **ABLEDATA, 8630 Fenton St., Ste. 930, Silver Spring, MD 20910; (800) 227-0216 or (301) 608-8998 (voice); (301) 608-8912 (TTY); (301) 608-8958 (fax); Web site: http://www.abledata.com.**

CONTEMPORARY ISSUES IN EPILEPSY, PART 1

Overview From the Editor-in-Chief

In 1999, *EXCEPTIONAL PARENT* magazine published a special series, *The Changing Nature of Epilepsy: New Patterns of Care for the 21st Century* devoted to reviewing currently available diagnostic methods and tools, as well as medical and surgical treatments (see box below). It also tried to anticipate what new approaches would be available in the new millennium, in which we now find ourselves.

This *EXCEPTIONAL PARENT* three-part series on epilepsy—published December 2000 and February and March 2001—is devoted to a more personal but no less important topic: what parents need to know about childhood seizures. Specifically, we will try to summarize the information that often does not get adequately addressed during an office visit. The focus of this series is not on extolling new therapies that have just arrived or that we think may be on the way, though these are very important, but on what is currently known. We have assembled an experienced group of writers and hope that you, the readers, find it helpful.

For this the first installment in the series, I have written summarizing current thinking on the prognosis of childhood seizures, starting from diagnosis to remission. The message is that the medical prognosis is far better than we used to think, and that we are improving our ability to identify, early in the course of the disorder, those children who will do well, along with those who will not. However, we also discuss the increased understanding of the negative psychosocial aspects of childhood seizures, including their impact on education and future employment that requires parents to be both aware and involved. It is accompanied by a list of resource organizations that can be useful for parents and schools.

In future series installments:

- Patricia Crumrine, MD, (the director of the Pediatric Epilepsy Program, professor of pediatrics and neurology at University of Pittsburgh, Children's Hospital of Pittsburgh), discusses information that families of children with epilepsy need in order to talk about epilepsy and seizures with their child, as well as with his or her brothers or sisters, friends, other caregivers, and adults who are often with the child.
- Christine O'Dell, RN, MSN (a clinical nurse specialist in epilepsy at the Comprehensive Epilepsy Management Center at Montefiore Medical Center), summarizes what families need to know about recognizing seizures and providing both basic and advanced first aid to a child who is having a seizure. The article includes practical suggestions and "do's and don'ts" as well as advice on when to call 911.
- We review what some of the advances in our current knowledge of genetics mean to families of children with epilepsy. Gregory Holmes, MD (professor of neurology, Harvard Medical School, and director of the Center for Research in Pediatric Epilepsy, Children's Hospital, Boston, Massachusetts), reports on the role of genetics for those with epilepsy.
- There is also a summary of the recent "Conference for the Cure" sponsored by the National Institutes of Health, written by the Epilepsy Foundation.

Intertwined with this information by medical specialists in the February and March 2001 issues will be articles focusing on families with children who have epilepsy, providing first-hand experience from the perspective of parents. In addition, there are extensive resource citations, and identifying organizations as well as published, video, and Internet sources of information for parents and children. In this issue, we present an annotated reviewed list of useful Internet sites where families can log on for more information—and keep logging on in the future for updated information. As editor-in-chief of this series, I have personally reviewed this list. While I cannot take responsibility for the accuracy or validity of any specific items, they are all excellent sites that provide generally reliable and up-to-date information.

Putting this series together was an exciting and rewarding task. It is both challenging and fun to try and distill medical information into plain (or reasonably plain) English rather than the medical jargon we often publish. This is, after all, what we try to do every day when communicating with our patients in the office. Needless to say, a task like this is not accomplished without a lot of help. I thank all my colleagues for agreeing to write their articles and for getting them in on time. All the authors are indebted to our patients from whom we constantly learn. Thanks also to our editorial advisory board who reviewed the articles for content to provide peer review. We hope that you, our readers, find it rewarding.

Sincerely,
Shlomo Shinnar, MD, PhD
Professor of Neurology and Pediatrics
Director, Comprehensive Epilepsy Management Center
Montefiore Medical Center
Albert Einstein College of Medicine
Bronx, New York

The Changing Nature of Epilepsy: New Patterns of Care for the 21st Century reviews diagnostic and therapeutic treatments for epilepsy. This 38-page monograph derived from a special series of articles published in *EXCEPTIONAL PARENT* magazine from August to October, 1999, is available from the Exceptional Parent Library: telephone, (800) 535-1910; Web site: http://www.eplibrary.com.

This is the first of three installments made possible by an unrestricted educational grant from Élan Pharmaceuticals

CONTEMPORARY ISSUES IN EPILEPSY, PART 1

Prognosis for Epilepsy

Shlomo Shinnar, MD, PhD

Not so long ago, almost all children with seizures were placed on long-term therapy with medications to prevent seizures (antiepileptic drugs). This approach was based on several assumptions: First, that almost all children with an isolated seizure would go on to have more seizures. Second, that seizures, even brief ones, could cause brain damage and lead to progressively intractable (difficult to control) epilepsy. Third, that early therapy with medications not only prevented seizures but also somehow altered the natural history of the disorder and prevented the development of "chronic" epilepsy. Finally, that antiepileptic drugs were not only effective but also safe, and that treatment was associated with only minimal side effects. Epilepsy was thought of as a progressive, lifelong disorder with a high morbidity and mortality, and a poor prognosis. Psychosocial outcomes—the social, educational, and behavioral outcomes of children with epilepsy and its treatment—were rarely discussed, though they were assumed to be poor. The focus and emphasis of treatment was on trying to prevent any seizures at all costs. We now know that these assumptions are not true.

Over the past several decades, a large body of data has accumulated that challenges these assumptions. The prognosis of epilepsy in terms of becoming seizure free is much more favorable than we thought. Many children with a single seizure do not go on to experience further seizures. Many children with epilepsy ultimately become seizure free, allowing antiepileptic drugs to be withdrawn after a relatively short seizure-free interval. In fact, many if not most children with seizures have a relatively mild disorder. Recent data also suggest that seizures, while frightening events, rarely cause brain damage. In children, even prolonged seizures rarely cause brain damage unless they are associated with an acute neurological insult such as meningitis or head trauma.

On the other hand, there is now much more emphasis on the psychosocial outcomes of children with seizures. Recent data suggest that even though seizures may become less severe, infrequent, or even disappear, having childhood seizure's may have a lasting negative impact on educational achievement, employment, marriage, and other spheres of life. This article will summarize what is currently known about the long-term prognosis of children who have seizures. Note that we are talking about unprovoked seizures, which should be distinguished from febrile seizures—the latter common in children and usually completely benign.

Shlomo Shinnar, MD, PhD

PROGNOSIS FOLLOWING A FIRST SEIZURE

Approximately one-third to one-half of children and adults with seizures will initially come to medical attention following a single seizure. The other one-half to two-thirds will already have a history of prior events, though they—or, in the case of children, their parents—may not be aware that seizures have occurred before. For example, the child who is brought in having had a convulsion may, on questioning, have a history of staring spells that turn out to have been seizures. These are more properly called "newly diagnosed epilepsy" and usually require treatment.

If we carefully follow over time the group that came to medical attention after the first seizure, the current best estimates are that approximately 40 to 50 percent will have another seizure. Most children who will have another seizure do so early, with over 50 percent of recurrences occurring within six months of the initial seizure and over 80 percent within two years. Children at higher risk for having more seizures are those who have other neurologically problems (such as mental retardation, cerebral palsy, or autism) or have an abnormal electroencephalogram (EEG) or imaging study (CT scan or MRI). Duration of the initial seizure does not seem to influence whether or not there will be another seizure. Children with a long first seizure—even one lasting 30 minutes or more—have the same chance as other children of having more seizures. However, if they do have more seizures, there is a good chance that those, too, will be prolonged. Parents need to discuss what to do if that happens with their physician. (Later in this series, we will discuss "First Aid for Seizures".)

The long-term prognosis of children who initially present with one seizure is usually favorable, even if they have further seizures in the short run. Treatment with antiepileptic drugs following a first seizure has been shown to lower the risk of further seizures by about 50 percent but to have no effect on long-term prognosis. That is to say, it does not affect the chances of the child eventually becoming seizure free. For this reason, a growing number of neurologists (including the author) do not place children with one seizure on long-term antiepileptic drug therapy, but wait until at least two seizures have occurred.

REMISSION ON OR OFF MEDICATIONS

What happens to children who do meet the criteria for epilepsy, generally considered as having two or more seizures more than 24 hours apart? (This definition excludes those who have an isolated flurry of initial seizures on one day. Their prognosis is the same as those with one seizure.) Approximately 70 percent of children with epilepsy will eventually enter remission, defined as being seizure free either on or off medications. Factors that affect the likelihood of achieving remission include whether the child has other neurological disabilities, the age of onset (when seizures started) and the specific epilepsy syndrome.

Children with other significant neurological disabilities (such as mental retardation, cerebral palsy, or autism) have a smaller chance of attaining remission and a higher risk of developing intractable epilepsy (frequent seizures despite treatment). However, available data suggest that, even in this group, almost half the children will eventually attain remission. Other milder neurological disabilities (for example, learning disabilities such as dyslexia or attention deficit disorder) do not alter the prognosis for remission. Children whose seizures begin prior to adolescence (age 10 or 12) have a higher chance of becoming seizure free than those with adolescent onset. There is some debate about whether children whose seizures begin in the first year of life have a worse prognosis.

Over the last decade, increasing attention has been given to the effect of the specific epilepsy syndrome on prognosis. It appears that this may well be the most important predictor of long-term prognosis, including whether the child will become seizure free on medications or develop intractable seizures and whether they will be able to successfully discontinue medications if and when they become seizure free.

What about those children whose seizures are uncontrolled with medications? In some, newer therapeutic and diagnostic treatments, such as surgery and new drugs, offer hope for remission. We are now using epilepsy surgery much earlier than in the past for those children whose epilepsy syndrome can be treated surgically. However, even in those children whose seizures are uncontrolled and who are not candidates for surgery, prognosis is often not as bleak as was previously assumed. While those who respond early to therapy clearly have a better prognosis for remission, many children who do not respond initially do eventually attain remission. One study examined children with refractory epilepsy, many of whom also had other neurological disabilities. Twenty years later, almost half of these children—now adults—were either seizure free or had only occasional seizures. These data are on patients who were treated prior to the wide access to new drugs and other therapeutic treatments that are now available.

WITHDRAWING MEDICATIONS IN CHILDREN WHO ARE SEIZURE FREE

A large number of well-designed studies involving several thousand children have been done with remarkably similar results. Between 60 and 75 percent of children with epilepsy who have been seizure free for more than two or four years on medications remain seizure free when medications are withdrawn. Chances for successful medication withdrawal are influenced by neurological status, age of onset, the EEG, and the specific epilepsy syndrome. The children with the most favorable prognosis are those without other neurological disabilities, age of onset under 12, and a normal EEG prior to medication withdrawal. These children have a better than 80 percent chance of successfully coming off medications. Children with age of onset 12 or older and those with abnormal EEGs have an approximately 50 percent chance at successful medication withdrawal. The influence of the particular epilepsy syndrome as a key determinant of prognosis is discussed in the next section. Seizure type, the specific antiepileptic drug used, the drug level prior to discontinuation, and the duration of active epilepsy prior to becoming seizure free have not been consistently associated with the risk of recurrence.

Children with other neurological disabilities are less likely to become seizure free to begin with, and less likely to successfully come off medications if they do become seizure free. In the past, these children were, therefore, usually left on medications indefinitely. It is now recognized, however, that while the risk of recurrence is higher, almost half of those who are seizure free on medications can eventually be successfully withdrawn from them. The ones with a poor prognosis for successful medication withdrawal are those with significant mental retardation (an IQ under 50) and those with age of onset 12 or older.

While puberty is frequently mentioned in discussions of prognosis and medication withdrawal, there are no convincing data that withdrawing medications during puberty is associated with a higher risk of recurrence. Studies on the remission of seizures and on withdrawing medications do not show a reproducible pattern that correlates with puberty. The probability of remaining free from seizures after medication withdrawal is more a function of the underlying cause, age of onset, and the specific epilepsy syndrome.

Parents frequently ask, "What will hap-

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pen if seizures do recur?" The majority of children who relapse after medication withdrawal will become seizure free after medications are restarted, though not necessarily immediately. The risk of serious injury from the recurrence of seizures is low. The prognosis for reentering long-term remission appears to be primarily a function of the underlying epilepsy syndrome. One well-designed study of medication withdrawal in children and adults found that the prognosis for seizure control after recurrence in patients with previously well-controlled seizures was no different than for those who were withdrawn from therapy and relapsed or for those who relapsed while remaining on therapy.

There appears to be little difference in recurrence risks when medications are withdrawn after a child has been seizure free for two years or after four years. In general, the author of the study recommends a two-year seizure-free interval prior to attempting medication withdrawal. In selected children with mild seizure disorders and favorable risk factors, medication withdrawal can be considered after a shorter seizure-free interval, though the risk of further seizures is somewhat higher than after a two-year seizure-free interval. The majority of recurrences occur shortly after medication withdrawal: almost half the relapses occurring within six months of medication withdrawal and 60 to 80 percent occurring within one year.

In the past, some physicians have used slow schedules for tapering off medications, thinking that they would thereby reduce the risk of recurrence. A recent clinical trial compared a rapid, six-week medication tapering off after two seizure-free years with a more gradual nine-month tapering off and found no differences between the two groups in the risk of recurrence. While abrupt discontinuation is not recommended, there is little scientific rationale for a slow tapering off in most cases. Adolescents, in particular, feel rapid tapering off is important, since we generally advise them to stop driving for six months to a year following medication withdrawal.

PROGNOSIS AND EPILEPSY SYNDROME

We increasingly recognize that the major determinants of prognosis are the underlying cause of the seizures and the epilepsy syndrome. These factors are key to whether the child will attain remission or become intractable, whether he or she will be able to come off medications, and whether or not there will be a gradual deterioration in cognitive function over time. The underlying syndrome influences these factors more than seizures themselves. This new information strongly influences treatment decisions. Some syndromes are now recognized to be self-limiting and benign. We often do not treat them at all. Others are recognized as progressive disorders and/or medically refractory early on, and are candidates for aggressive early intervention using both medical and surgical approaches. With increased sophistication in recognizing epilepsy syndromes, a much better understanding of the prognosis can be reached.

What is an epilepsy syndrome? Parents are usually aware of seizure types, which is what they observe. A syndrome, however, is a constellation of findings, including seizure type or types, the specific EEG and imaging findings, the age of onset, the underlying cause (if known) the presence of other neurological findings, and the pattern of the seizures (for example, occurring when asleep vs. awake or whether they are short vs. prolonged). When combined, these allow us to diagnose a specific epilepsy syndrome. For example, the diagnosis of childhood petit mal includes an age of onset between 3 and 12, absence seizures triggered by hyperventilation, and a specific EEG pattern of three-per-second spike and wave. Just having staring spells is not enough. For temporal lobe epilepsy, there must be—in addition to the appropriate seizure types—EEG or imaging evidence that the seizures arise out of the temporal lobe rather than from a different area of the brain.

SOCIAL AND EDUCATIONAL OUTCOMES

While studies of seizure outcomes have shown that the prognosis for becoming seizure free is much better than previously thought, studies of social and educational outcomes have raised some concerns even about children with mild seizure disorders. A recently published study of childhood-onset epilepsy in Finland that followed children with epilepsy for over 30 years, starting in the 1960s, found that even children with epilepsy and no other neurologic disabilities had a much higher likelihood of going no further than a primary education. This was true even in those with the mild self-limiting forms of childhood epilepsy. Studies in the United States of patients attending seizure clinics have reported academic underachievement in relation to that expected of children with similar IQs, and a higher proportion of unfavorable educational outcomes. A Canadian study that compared children with typical absence (petit mal) epilepsy to children with juvenile rheumatoid arthritis found that those with epilepsy had greater difficulties in academic and behavioral domains than those with arthritis. While children not in remission did worst, even those children in remission did worse than the children with arthritis.

The Finnish study also found that even the mildest form of childhood epilepsy can have a lifelong impact on future social outcomes. It was reported that those with childhood-onset seizures also had a lower rate of being married or having their own children, as well as a marginally lower probability of being employed. These findings are the same even if one limits the analysis to those with epilepsy syndromes that are considered relatively benign. Many of these cases had been seizure free and off medications prior to age 20, and still had some difficulties many years later. Thus, these adverse social effects may persist even in those who entered adult life seizure free and off medications. Several studies of adults with active epilepsy indicate that they have lower rates of both employment and marriage than that of comparable general population groups. The differences were attributed to discrimination and to problems related to the active seizure disorder. Studies of refractory childhood epilepsy also report poor long-term employment outcomes and lower rates of marriage, even if they later became seizure free.

There are several possible reasons why children with epilepsy have poorer educational and social outcomes. First is the underlying brain abnormality that gave rise to the seizure disorder. There is a higher rate of learning disabilities in children with epilepsy even if they are of normal intelligence. The impact of seizures themselves is probably limited to the group with frequent seizures. There is some evidence that frequent abnormal discharges that can be seen on the EEGs of some children may be associated with cognitive impairment even without actual seizures—though what to do about this is controversial. The impact of chronic drug therapy should not be minimized. It is now recognized that antiepileptic drug therapy is associated with a variety of adverse effects on cognition and behavior. While the publication of these studies is recent, they are often reporting outcomes of patients who were treated many years ago. Many of the children reported on in these studies, including the Finnish one, were treated with phenobarbital, one of the worst offenders in terms of these effects.

In addition, one should not underestimate the effects on academic performance, behavior, or emploment opportunities, of both discrimination and of labeling. The negative impact of discrimination, particularly on employment, is clear. Less obvious is the impact of labeling and diminished expectations. If the school, parent, child, or any combination of these expect that the child will achieve less due to the epilepsy, this can become a self-fulfilling prophecy. Furthermore, if any problems arise in school, they are then blamed on the epilepsy instead of searching for a specific learning disability such as attention deficit disorder or dyslexia, which can be remedied.

The above discussion of possible causes suggests some of the solutions. Often, we cannot alter the underlying biology. However, we now carefully weigh the possible adverse effects of medications. Drugs*such as phenobarbital are not recommended for first-line use in school-age children—even though they are effective—due to their cognitive side effects. Children who are not achieving their expected potential should have: a thorough evaluation for remediable causes including an evaluation of possible subclinical seizures (seizures that may not be recognized by those around them); an evaluation of possible medication effects; neuropsychological testing to determine any specific impairments as well as specific strengths the child may have; and an assessment of any social factors that may be interfering with academic achievement. It is important to remember that while a higher proportion of children with epilepsy have difficulties, the majority do well.

SUMMARY

Studies of childhood-onset seizures now show that the prognosis for seizure remission is favorable in the majority of cases. Even children with other neurological disabilities often do well. Furthermore, we can now better identify early in the course of the seizure disorder those likely to do well and those likely to have problems, and target the latter for more aggressive intervention. Recent studies have also indicated that educational and social outcomes are an area of concern. This is also an area of opportunity since many of the causes of these social outcomes are potentially reversible. It is also important to remember that the majority of children with epilepsy do well in all areas. The focus of epilepsy care, particularly at comprehensive epilepsy centers (see below), has changed now from simply getting seizures under control to producing an optimally functioning adult. Parents can and should be active participants in this process.

Shlomo Shinnar, MD, PhD, is Professor of Neurology and Pediatrics and Director of the Comprehensive Epilepsy Management Center, Montefiore Medical Center, Albert Einstein College of Medicine, Bronx, New York.

COMPREHENSIVE EPILEPSY CENTERS

What are they?

Comprehensive epilepsy centers, also known as comprehensive epilepsy programs, specialize in the diagnosis and treatment of epilepsy. In general, they have a staff that includes neurologists specializing in epilepsy, neurosurgeons, neuropsychologists, clinical nurse specialists, and social workers, all working as a multidisciplinary team geared to a comprehensive approach to the patient.

What services do they offer?

In general, they offer sophisticated diagnostic techniques including video EEG monitoring and magnetic resonance imaging (MRI) with special protocols designed to detect seizure-related abnormalities. Available treatments include optimum selection and dosing of available seizure medications tailored to the child's specific epilepsy syndrome, and specialized medical regimens, including steroids, ketogenic diet, and access to new and experimental drugs. Evaluation for surgery and epilepsy surgery are generally also best done at these centers, as are new procedures such as the implant of the vagus nerve stimulator.

In addition, coexisting conditions, including cognitive, academic, and behavioral problems, are addressed. For example, neuropsycological testing, may identify remediable cognitive deficits.

The staff is also able to educate parents and help intervene when necessary in the child's school.

Who should go there?

Many children with uncomplicated epilepsy are adequately cared for by their pediatrician or child neurologist. However, if a child is still having seizures after a trial of two medications, is having unacceptable side effects from medication, or is experiencing cognitive or behavioral problems whose cause is not fully clear, then a referral to a comprehensive epilepsy center is appropriate. Certain difficult-to-treat specific epilepsy syndromes such as infantile spasms or Lennox-Gastaut also often benefit from an evaluation at a comprehensive epilepsy center. Most of these centers are able and willing to do the evaluation, make recommendations, and work with the family's child neurologist in managing the child's seizure disorder, especially if distance makes it difficult for the family to have management undertaken solely at the comprehensive epilepsy center.

What to look for

There is general agreement as to what a good comprehensive epilepsy center should include. Unfortunately, there is no licensing or certification—anybody can call themselves an epilepsy center. Parents should look at whether the institution has a good reputation, whether the staff includes a multidisciplinary team (or only a single doctor with a sign), and whether there is an inpatient epilepsy monitoring unit. Parents should also explicitly inquire about the presence of a child neurologist with specific expertise in epilepsy. Some epilepsy centers have considerable experience with adults, but do not have a child neurologist even though they do treat children. The availability of a child neurologist is critical, and of particular importance for younger children.

How to find a comprehensive epilepsy center

There are several approaches. Recommendations from family physicians can be useful. The child's neurologist can be an invaluable resource. The Epilepsy Foundation maintains a list of epilepsy programs across the nation, though it neither certifies nor rates them. Local epilepsy societies can often recommend an appropriate center. It can also connect parents with other parents of children with epilepsy who can share their experiences with centers they have tried near at hand.

Fortunately, there are a number of good centers, and with a little research it is not difficult to find one.

Resources

ORGANIZATIONS

The Epilepsy Foundation
4351 Garden City Dr.
Landover, MD 20785-2267
(800) 332-4050 (library)
(800) 332-1000
(toll-free information line)
(301) 459-3700; (301) 577-2684 (fax)
Web site: http://www.epilepsyfoundation.org

The Epilepsy Foundation is a nonprofit, voluntary organization with affiliates nationwide. It works for children and adults with epilepsy through support of research, education, advocacy, and service. Its goal is to empower parents with information they can use. The organization supports research into childhood and other forms of epilepsy to improve care and, eventually, to find a cure. It is committed to helping every child achieve the very best possible quality of life.

The Epilepsy Foundation's Web site offers news and information on an ongoing basis. Its national toll-free telephone line is another source of information, as is its National Epilepsy Library. The group's annual national conference brings together experts in the field to review advances and challenges.

Foundation affiliates across the country can provide parents with information and education about epilepsy and parenting, parent-to-parent and parent-support groups, programs for children (such as camping and family recreation), respite care when children have severe and frequent seizures, people who can help with school planning, special seminars and conferences, and—on a limited basis—travel assistance funds when children need out-of-town medical care. For more information about these funds, call (301) 459-3700.

The Epilepsy Foundation has designed a variety of publications and other materials just for children (including the quarterly publication *KidsNews*). An Internet Teen Chat Room for older children—http://www.teenchat.org—is part of that effort.

Membership in the Epilepsy Foundation includes discounts on selected organization material; a subscription to the organization's newspaper, as well as *KidsNews*; and access to mail-order pharmacy services. For more information, call (800) 213-5821 or visit the organization's Web site.

Epilepsy Canada
1470 Peel St., Ste. 745
Montreal, Canada H3A 1T1
(514) 845-7855; (514) 845-7866 (fax)
E-mail: epilepsy@epilepsy.ca
Web site: http://www.epilepsy.ca

Epilepsy Canada provides information on epilepsy, networking opportunities, and advocacy for both people with epilepsy and parents of children with epilepsy. The organization is connected with a system of province-oriented and local affiliates throughout Canada.

In Canada, organizations approach advocacy efforts directed at government bodies through the National Voluntary Health Agency and the Canadian Center for Philanthropy. Epilepsy Canada can provide information about these efforts as well as about federal and province laws and regulations.

American Epilepsy Society (AES)
638 Prospect Ave.
Hartford, CT 06105-4240
E-mail: info@aesnet.org
Web site: http://www.aesnet.org

American Epilepsy Society (AES) promotes research and education for professionals dedicated to prevention, treatment, and cure of epilepsy, including physicians, scientists, researchers, and other professionals in the field. A national conference is held annually.

ON THE INTERNET:

This listing of Web sites, with the exception of two (Epilepsy Canada and Yahoo Health: Neurological Diseases), was adapted from PATIENTWEB.COMpendium™. The Medical Reference Guide to the Internet, General Neurology, Spring 2000. *This pamphlet of sites for professionals and consumers is available from WEB DIRXTIONS by visiting their Web site (http://www.webdirxtions.com) or faxing your request to (973) 916-0021.*

SPECIFIC EPILEPSY SITES

Epilepsy Foundation
http://www.epilepsyfoundation.org

Sections on the Web site include Research in the Field of Epilepsy, Advocacy and Legislation, Information and Education Resources, News and Publications, Programs and Services, and Kid's Club, an area for children and young adults with epilepsy. Check out the Report to the Nation, in the News section, for valuable information about epilepsy in America. The online newsmagazine *EpilepsyUSA* is also a useful resource for patients and their physicians to review. And don't miss the Epilepsy Foundation Chat Room: http://www.epilepsyfoundation.org/programs/chatrule.html.

Epilepsy Canada
http://www.epilepsy.ca

This site provides information on the organization; its goals and national programs; partners, and membership; basic facts about epilepsy; research projects and programs (including the Gene Discovery Project); coping with social issues (ranging from "living with epilepsy" to "recreational and safety tips"); and diagnosis and treatment. Its Kidz Korner is designed to educate a child about "How Seizures Happen," medication, and first aid. There is also information about Epilepsy Canada materials for adults and children. In English and French.

Epilepsy International
http://www.epilepsy-international.com

The goal of this site is to be the definitive site for epilepsy and its issues. The site seeks to meet the needs of patients and healthcare professionals by offering several levels of information. Sections include a bulletin board discussion area, information on drugs, professional associations/ organizations, a professional resource center, a medical reference section with abstracts from recent professional meetings, and a section about the history of epilepsy, including famous people with the disorder. There is also a link to a mirror site for Spanish-speaking visitors.

American Epilepsy Society (AES)
http://www.aesnet.org

Although primarily aimed at professionals, consumers will also find much useful information on the AES Web site. The site also provides access to NeuroCentral, the official educational site of the AES, for the exchange of research, treatment, and management data concerning seizure disorders.

GENERAL NEUROLOGICAL SITES

American Academy of Neurology
http://www.aan.com

The Amercian Academy of Neurology (AAN) Web site is a great resource for parents of children with epilepsy and other neurological disorders. This comprehensive site includes information about the field of neurology, as well as a searchable directory to find a neurologist. The Resources section contains information about publications, including full text and abstracted articles from *Neurology*, the official journal of the AAN.

MedMark: Medical Bookmarks
http://medmark.org/neuro

The MedMark site is basically a catalog of neurology Web sites organized by categories. The sections on the MedMark site include News, Associations/Societies, Diseases, Atlas/Images, Journals/Books, and miscellaneous Resources. Some sites in the directory are listed as "BEST"—highlighting them as the leading sites in this section. A number of the sites also contain brief summaries that enable users to scan for sites of interest without visiting all of them individually. Overall, the MedMark site is a great starting point and general resource for finding the best sites related to neurology on the Web.

National Institute of Neurological Disorders and Stroke
http://ninds.nih.gov

This site from the National Institutes of Health (NIH) is a great information resource for both patients and physicians. Although the site is intended as a resource for distributing information about discoveries in neuroscience, it also does an excellent job of providing a wide range of information to a professional and general audience. The "Patients" section of the site contains information on publications, treatment studies, and other health organizations.

Nervous System Diseases National Guideline Clearinghouse
http://www.guideline.gov

This Web site is a service of the National Guideline Clearinghouse (NGC), a public resource for evidence-based clinical practice guidelines. The NGC is sponsored by the Agency for Healthcare Research and Quality (formerly the Agency for Health Care Policy and Research) in partnership with the American Medical Association and the American Association of Health Plans.

The site is an index of structured summaries of evidence-based clinical practice guidelines from various organizations. Users can select the "compare guidelines" feature for a side-by-side comparison of target populations, review methods, and quality of evidence. Users can also link to full text for the guidelines, which are located on the NGC site and at other Web locations. There are currently over 90 guidelines available online in the field of neurology.

Internet Grateful Med
http://www.nlm.nih.gov
The Internet Grateful Med Web site is available as a free service from the National Library of Medicine for health professionals and health consumers to search for clinical information online. The site enables users to search the vast MEDLINE database of clinical article abstracts.

Ever since the national Library of Medicine made MEDLINE and other database search services available to the general public online, use by health professionals and consumers has continued to grow at a rapid pace. Users can search most databases by keywords, such as a drug name or disease; however, the search service is much more useful if searches are targeted to specific keywords to avoid sifting through thousands of irrelevant article abstracts. Users who wish to read more than the free abstracts online will need to use the Loansome Doc service. The service requires the user to coordinate through a medical library—often at an academic hospital or medical school—to receive the actual article by mail or fax. The site also offers access to MEDLINEplus, which enables consumers to search for disease information by category or by keyword.

NOAH: New York Online Access to Health
http://noah.cuny.edu
Despite the challenging color scheme of this Web site, the ASK Noah Web site offers a comprehensive listing of other Web sites and health information resources online—including numerous sites in the field of neurology. Visitors can choose from an English or a Spanish version from the home page to continue in the language of their choice.

Chose "Health Topics" from the main page and find the link to the neurologic disorder area of the site. One of the topics in the neurology section is epilepsy. It has a page of links organized into such categories as background of the disease, care and treatment, complications, and additional resources.

PEDIATRIC NEUROLOGY SITE

Child-Neuro Home Page
http://waisman.wisc.edu/child-neuro/index.html
The main purpose of the Child-Neuro Web site is to coordinate the available Internet resources in child neurology, for both professionals and parents. Although the site is lacking in terms of independent context, it is the best site available in the field of child neurology. The site is useful for professionals and consumers alike.

Sections on the site include "Books," "Journals," "Parent Information," "Pharmaceutical Information," "Research in Child Neurology," and "Internet and Neurology," an online course.

IN ADDITION...

BROWSER RESOURCE SITE
Yahoo Health: Neurologic Diseases
http://dir.yahoo.com/health/diseases_and_conditions/neurological_disorders
This is the Internet address that will allow you to use Yahoo's health information resource. It is a starting point for searching for information about neurological diseases, including epilepsy.

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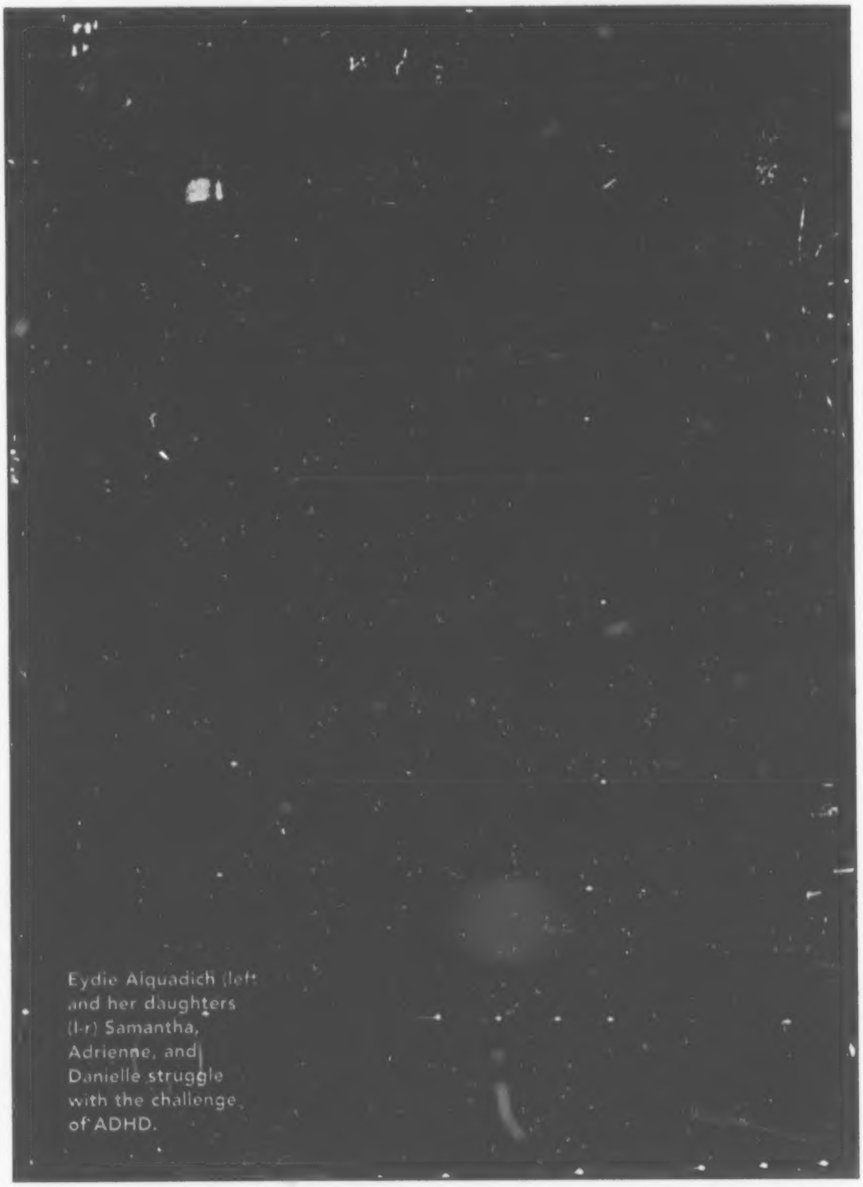
ADD/ADHD

All in the Family

by J. Carlisle Spivey



Eydie Alquadich (left and her daughters (l-r) Samantha, Adrienne, and Danielle struggle with the challenge of ADHD.

Eydie and Mitchell Alquadich are very familiar with attention deficit disorders (ADD and the hyperactivity version, ADHD). Each of their three daughters—Samantha, 15, Adrienne 13, and Danielle, 9—has her own version of attention deficit disorder and associated conditions.

There has never been a specific gene identified as "the ADD gene." Stewart Mostofsky, MD—a child neurologist and researcher in ADHD at The Kennedy Krieger Institute in Baltimore, MD explains that there is little knowledge about how genes are involved in ADD or ADHD. He says, however, that family studies and studies of twins strongly suggest a genetic component. Eydie Alquadich is convinced of it.

Though never diagnosed with ADHD, Eydie struggled throughout her school years with concentration difficulties and a roaring energy level that made focusing a hardship. When she became aware of attention deficit disorders, they seemed to describe not only her own experience, but that of her brother and sister, as well as her father and his four brothers—who grew up long before ADD or ADHD were identified.

First up

When Samantha Alquadich went to first grade, it was evident that something was wrong. She was a bright child and quite able, but with overwhelming energy. Concentrating was very difficult for her. Preschool teachers had been able to work

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with her and help her focus on tasks at hand. But now she had a teacher who could not handle the situation. The principal, too, was unconvinced that the issue was more than a discipline problem.

Researching the school systems in the immediate area, Eydie and Mitchell selected the one they felt could respond best to Sam—and moved there. Even without a diagnosis of ADHD at that point, Eydie knew from her own experience with the disorder that having excess energy can get in the way of concentrating on learning. Just as she had learned to channel that energy into extra activity (intellectually as well as physically) for herself, she and her husband decided to channel Sam's extra energy at school. They chose a Japanese emersion program in which Sam learned all her regular subjects in Japanese. She had to concentrate twice as hard to get her work done. The need to focus on a new language as well as on new lessons, helped drain her abounding energy and center her attention. Now Sam not only excels in reading and math, she is also fluent in Japanese.

Sam's parents also looked for things outside of the family and school to keep her focused. From second to sixth grade, she was involved in gymnastics and dance programs. Since then, dance has provided the major outlet. She has trained in all kinds, but most loves jazz and lyrical dance.

Until Sam was 13, to help keep her focus on tasks at school and at home, she and her parents began behavior modification counseling at Kennedy Krieger Institute, not far from the Alquadich home. The counseling had just begun when puberty hit, hormones kicked in, and control went out the window.

Above: The Alquadich sisters (l-r) Danielle, Sam, and Adrienne are coping with their ADHD.
Left: Samantha, is a member of her school's dance team.

In the middle

The Alquadich's second daughter—Adrienne—had a very different history than her older sister. When she entered school, she had a great deal of difficulty learning to read. Her parents decided to send her for tutoring, where she was taught phonetically. "We accidentally did the right thing for her, as we had done for Sam," says

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Eydie. "We had no idea what was behind her difficulties."

Adrienne would tune out from all around her. "It was very subtle," notes Eydie, "That made it harder to help her. She would zone out, but not have the self control to zone back in again."

When she was in third grade, Eydie heard of a program at George Mason University in northern Virginia where Adrienne could be tested for either emotional or learning disorders. The results were clear: she had a learning disorder (LD). But, since this was an academic program, the evaluators were only interested in identifying, rather than treating, problems. No recommendations were made.

> **"Follow your instincts. If you think there is something wrong, there is. Don't let people tell you otherwise."**

Once again

Danielle's difficulties were recognized when she was an infant. She had delays in the usual vocal patterns from birth. The pediatrician said she was fine, but Eydie had her doubts and insisted that Danielle be tested.

At 20 months, Danielle was diagnosed as a "delayed speaker." "That was our first 'tag'," Eydie explains. Once they had a diagnosis, they could go to the public school system to establish an early intervention plan through the Child Find program, the county's early intervention program. "I found out about it by asking around," says Eydie. As part of that plan, the county assigned a speech therapist to work with Danielle.

By age 3, Danielle was still not talking. From her own college courses and her teaching certificate, Eydie knew something was seriously wrong. "Danielle was dying for social contact with other children," her mom reports. "She couldn't talk, so she responded to them physically, grabbing at them. When she was rejected by both children and adults, she would get angry." Emotional trauma set in.

Finding out

By the time Danielle was 6, Eydie had exhausted all known possibilities. She heard through a friend about testing at Kennedy Krieger. "I pushed, and argued, and cajoled, and pleaded," she says, "and I finally got my way."

The tests resulted in a new tag for Danielle: "processing disorder." She had been struggling, not just to make sounds, but with the laborious process of understanding the meaning of words. She could be shown three objects—a book, a toy, and a shoe. If told, "Danielle, point to the book," she could do so. But if you put the book into her hands and asked, "Danielle, what is this?" she could not find the word.

In light of her new diagnosis, Child Find suggested an LD center for Danielle, one which was used to working with kids with learning disabilities. There Danielle could be taught how to use words. At the same time, she would work on her socialization skills, learning how to approach and interact with other children as well as with adults. By the time she was 4, Danielle could communicate well enough to start making some friends, and prepare for kindergarten.

With kindergarten, Danielle was discharged from the Child Find program. It was decided that, since she could now go to school, she must no longer need their help. "In kindergarten and first grade, she learned nothing," reports Eydie. "She became depressed because she knew she wasn't learning." Eydie would try to teach her at home after school. When Danielle turned to her one day and said, "Mommy, I wish I could die," Eydie knew something had to be done. She kept demanding help, and she found cohorts: Danielle's teacher, and the school principal.

Together they fought the system, emphasizing that Danielle had emotional problems as well as learning difficulties. As Danielle was leaving first grade, a new learning disability (LD) program was just starting—she was the first accepted. Danielle started the program in the fall with a one-on-one student/teacher ratio. "Second grade was the best year she ever had," Eydie says.

However, by the end of the first grade, Eydie had lost patience and returned to the Institute for further tests. There, they were able to fine-tune the "processing disorder" tag and gave a final diagnosis: ADHD and phoneme dyslexia. Along with their diagnosis, the specialists at the Institute wrote the IEP (individual education plan) for Danielle's school to follow. The IEP included a once-a-week appointment with a learning specialist who would work with both Danielle and her school's program.

The next step

Once Danielle had been evaluated as having ADHD, Eydie wanted Adrienne and Sam tested too. "It was a tough decision; insurance picks up nothing." Sam, then 13, was diagnosed with ADHD and oppositional defiant disorder (OD); Adrienne, with ADD and phoneme dyslexia.

Ritalin was prescribed for each girl. It was also suggested that Sam meet with a counselor to learn to better communicate with her parents, teachers, friends, and others. For Adrienne, tutoring was made available. Something "kicked in" half way through fifth grade—the C student began making As.

At the same time, Danielle started special LD classes as well as treatment through behavioral modification. The entire family attends counseling and behavior modification training so that children and parents with ADD/ADHD or not—understand and can cope with each other.

Eydie and Mitch's great adventure

Parenting any child can be a wild, hair-tearing, rewarding, confusing, invigorating, exhausting adventure in helping someone build a life. When your child has attention deficit disorder, it is all the more so, and when you have three...

Eydie is convinced that her girls' ADD and ADHD actually helped them make it through the "discovery" years of search and delay. Their energy was so enhanced that, rather than retreat, it drove them to find ways cope and even achieve, despite their individual disabilities. Because they had to be doing something all the time, they were highly motivated to take on new tasks.

Her own experience with ADHD gave Eydie an understanding of the need to channel that energy to help her girls control manifestations of the disorders. It also gave her the will to fight. "Silence is the kiss of death," she warns. "You have to constantly get up and find out what's out there. Follow your instincts. If you think there is something wrong, there is. Don't let people tell you otherwise." Her own background in teaching, with an emphasis on children with disabilities, helped her a good deal. However, networking with other parents, she advises, is one of the best ways to find new ideas, tools, and professionals who can assist. "Pursue, pursue, pursue. Don't stop. Find out what's out there to improve your child's life." She also credits Kennedy Krieger not only with the ability to test and treat, but with carrying the kind of clout that makes school districts sit up and listen.

> **Their energy was so enhanced that, rather than retreat, it drove them to find ways to cope and even achieve, despite their individual disabilities.**

Happily ever after?

As any family with the appropriate age groups can attest, life with two teenagers and a preteen is never serene. But today Eydie and Mitch can see a clear path for each one of their daughters. Now that they all know what is going on and have a therapy plan and tools for each—and for the family—in place, the future is not a murky place that is completely out of control.

Sam, now 15, has been on the varsity Oakton High School dance team since she was a freshman. The team claims top honors in national competitions. She wants to be a lawyer or corporate CEO (her mom expects her to be president of the United States).

Adrienne, now 13, is more studious than athletic, though she, too, loves dance. Her report cards—with As and a few Bs—still reflect her academic turn-around. With medication, she continues to learn to self-monitor and to focus in on the task at hand. Her favorite subject is math and she loves art. Right now her career aspirations point toward becoming a veterinarian.

Danielle's experience with a combination of medication, behavior modification, and the combined expertise of the learning specialists at her school and at Kennedy Krieger has been a rousing success. At 9, she is so excited to discover that it IS possible to learn. Eydie recalls the first week of school this year: she came bounding home to exclaim, "Mommy, I love my life!" Her athletic interests include softball and basketball. Her bike riding abets her social life in the neighborhood. "She stops to talk to everyone!" Eydie exclaims. Danielle's new concept of the future is so full that she has a range of ideas of what she will be: a dancer, an artist, or a scientist. ■

Eydie and Mitch Alquadich live in Herndon, VA, with their daughters Samantha, Adrienne, and Danielle. Mitch, with degrees in structural engineering and architecture, runs his own hospital planning firm, MKA Associates. Eydie—who holds a BA in art, an MA in psychology, a teaching certificate, and a degree in interior design—has both taught and designed. Today she consults with architects and does all rendering for MKA Associates. They are both advocate parents.

POINTERS FOR PARENTS

Don't go it alone. Contact CHADD (Children and Adults with Attention Deficit Disorders) to find out if there is a local CHADD support group in your area—telephone: (301) 306-7070; Web site: http://www.chadd.org).

Pursue, pursue, pursue. CHADD can be a good starting point for finding information about ADD and ADHD and what parents can do to help their children and families.

A FAMILY-PROFESSIONAL PARTNERSHIP

by Merle McPherson, MD, MPH, Gloria Weissman, and Bonnie Strickland, PhD

Judie Walker, the parent of an 18-year-old son with cerebral palsy and asthma: "Our medical home is a place where they know my story, they listen to my son, and they respect us. They facilitate our services and recognize these service needs beyond medicine. They talk with us."

Partners In The
Medical Home Project

The medical home is defined by the American Academy of Pediatrics (AAP) as an approach to care that is "accessible, family-centered, continuous, comprehensive, coordinated, compassionate, and culturally competent." Stated more simply, a medical home represents an approach to pediatric healthcare in which a trusted physician partners with the family to establish regular ongoing healthcare. This kind of care is taken for granted by most families of typically developing children, but it has not been available for many children with special healthcare needs, particularly those with complex medical conditions.

What is a medical home?

•COMMUNITY-BASED

Children with special healthcare needs surely deserve the same level of regular care that other children in their families and communities receive. Often they are able to access specialty care, but lack access to primary care services in the communities in which they live. For many years large numbers of these children lived and received their healthcare in settings that were segregated and separate from their families' communities, just as they received their education and child care in separate settings from other children. Most now live with their families, but their full inclusion in community-based healthcare has not occurred.

The medical home is a critical element in ensuring such inclusion for all children with special healthcare needs. It provides preventive, primary, and acute care that is geographically and financially accessible to all families of these children and available to them 24 hours a day, 7 days a week. The medical home assures continuity of care from visit-to-visit, from infancy through transition into adulthood. It creates a situation in which the healthcare professional, the child, and the family know each other well, trust each other, and are comfortable sharing information and asking questions.

John Gooch, the grandfather and primary care provider to his 4-year-old granddaughter who has microcephaly, is blind, and requires a wheelchair calls his medical home his "life preserver." He is able to talk to a "real person" anytime, is given time to talk about problems, and is asked questions.

•COORDINATED

Children with special healthcare needs require some level of specialty care. The medical home has a critical role to play in identifying with families, new needs as they arise, referring families to the right specialists at the right time, forming an effective working relationship with these specialty teams, coordinating care with those specialists, and helping families sort through and interpret the recommendations with those specialists. By doing these things, a well developed medical home increases the effectiveness of specialty care.

Mae Moore, the mother of a 5-year-old son with spina bifida, who is ventilator-

dependent, says of her son's physician: "He is the captain and the medical home is the ship on which we sail. Sometimes I have to give up fighting and let (him) carry on his battle. He communicates for me between other doctors who typically wouldn't listen to me."

A broad definition that encompasses children at risk may include as many if not more than one-third of the total child population.

Children with special healthcare needs also need a broad array of other community services, including those provided through early intervention programs, schools, and child care. The medical home can provide early referrals to these services, help families access them, provide valuable medical and health information to them, and participate in the development of Individualized Education Plans (IEPs) and Individualized Family Service Plans (IFSPs). By doing so, the medical home helps ensure that these children are able to succeed. For example, most children with special healthcare needs can participate in community child care, but that requires that the healthcare provider and child care provider work together. Ideally, the medical home, schools, and community agencies work together in a partnership that ensures that families receive ongoing communication, support, and coordination.

•COMPREHENSIVE

The medical home is intended to serve as one, very important component of an enhanced system of services for families and children that ensures inclusion by enabling these children to live, work, and play in their communities. By addressing the health and medical needs of the child in a comprehensive manner, the medical home provides a critical focal point and link within each community to ensure that children can live at home, attend their neighborhood school, and participate in all community activities like their peers.

Brad Geeck, the father of a 17-year-old daughter with autism reports that when he calls his medical home, "I know that they will know my daughter, her problems, and me. I get a fast response and people don't act as if we're strange."

Who are the children for whom medical homes are needed?

Who are the children for whom medical homes are needed? And why don't they have medical homes? The Maternal and Child Health Bureau of the Health Resources and Services Administration stated in the July 1998 AAP journal, *Pediatrics*, "Children with special healthcare needs are those who have or are at elevated risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children in general." According to a recent study, also cited in the journal, as many as 12.6 million children, representing 18 percent of the total child population, have a chronic physical, developmental, behavioral, or emotional condition that required health and related services beyond that required by children in general. This estimate does not include those at risk. A broad definition that encompasses children at risk may include as many if not more than one-third of the total child population. Furthermore, the incidence and identification of special healthcare needs varies among different age groups, and tends to increase as children mature.

For children with special healthcare needs who require a wide array of community services and supports, child health professionals themselves need more resources, information, and support.

What is the unmet need for the medical home?

An estimated 11.2 percent or 11 million children with special healthcare needs nationwide are uninsured, and many more are under-insured. Children without adequate insurance do not get adequate healthcare. In addition, 56 percent of children with special healthcare needs nationwide are without a usual place to go when sick or needing advice about healthcare.

A significantly larger number of children with special healthcare needs receive healthcare that is often difficult to access and inadequate to address the complex needs of this population and their families. These problems are often compounded for families living in poverty, in rural areas, and in disintegrating urban neighborhoods. Family Voices is a national network of families and advocates addressing health issues for these children and families. In reporting on its recent survey, Family Voices concluded that, "Families face a

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As part of this program, a medical home for EVERY child with special healthcare needs was established as one of six critical initiatives in acheiving comprehensive care.

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confusing maze of services from health plans, school systems, state agencies, and private agencies that are not well-coordinated.... Coordination of care and communication among providers are essential and must be improved to ensure quality care for children with special needs." Parents need information from their child health professionals not only about medical conditions and treatments, but about such areas as child rearing and development. Most of all, they need improved communication with these professionals. The Family Voices survey found that "Families of children with special health needs require more information and help in order to ensure a health system that works well for their child and family." For these reasons, the medical home concept has been endorsed by Family Voices.

What do providers need?

Child health providers also need more support in order to provide medical homes for families. For children with special healthcare needs who require a wide array of community services and supports, child health professionals themselves need more resources, information, and support. Pediatrician and researcher, David Hirsch, MD, has estimated the cost of providing a comprehensive medical home to a child with special healthcare needs to be approximately $81 per month, as compared with $16 per month for a typically developing child. Although enrollment of children with special healthcare needs in managed care is increasing, these arrangements are not yet consistently structured to meet the needs of these children and families. In striving to control costs, managed care plans may not include the broad range of service options required by children with special healthcare needs in their benefit packages.

In addition to good clinical skills, child health professionals need knowledge and skills in a variety of other areas in order to make the medical home a reality for their patients. They must be able to forge and maintain collaborative relationships with families, willing to explore all healthcare options with the families, and both wise and humble enough to acknowledge the expertise of parents in caring for their children. As one physician said, "It is not unusual for a parent to teach me about new aspects of her child's condition." They need to know how to support families in their central roles as care coordinators and create office environments and office procedures that are comfortable for all families.

What are federal and state programs doing?

The Maternal and Child Health Bureau implemented a national medical home initiative in 1997 in collaboration with the AAP. As part of this program, a medical home for EVERY child with special healthcare needs was established as one of six critical initiatives in acheiving comprehensive care. (The initiative addresses the problem of uninsured/under-insured families and emphasizes universal coverage.) The initiative had several purposes: (1) to establish partnerships with families in the planning, development, and oversight of the medical home; (2) to develop national models for providing medical homes to children with special healthcare needs; (3) to develop effective support systems for primary care providers serving these children; (4) to develop improved strategies for integrating health and medical services with the array of community services required by children with special healthcare needs; and (5) to improve families' access to medical homes.

The program has accomplished a great deal. A national training program, "Every Child Deserves a Medical Home," has been developed and implemented by the AAP in partnership with the Maternal and Child Health Bureau. Families have been active participants in the development and delivery of the curriculum for this training, which is designed to educate healthcare professionals, parents, and administrators on how to improve the delivery of services to children with special healthcare needs and their families. To date, 1,200 healthcare professionals have participated in the training. Follow-up and technical assistance at the practice level is currently being implemented. Providing a medical home for all children with special healthcare needs has been established as a core performance measure for the Maternal and Child Health Services Title V Block Grant Program. State Title V programs are now required to report annually on the extent to which children with special healthcare needs in the state

On the state and community level, elements of a medical home have been identified and cost estimates established and negotiated for providing a medical home for children with special healthcare needs in several pediatric practices.

have a medical home. Medical homes for all of these children is also included as an objective in the Healthy People 2010 National Health Promotion and Disease Prevention Objectives. A national survey has gone into the field, which will provide important data on national and state progress toward this goal by 2002.

On the state and community level, elements of a medical home have been identified and cost estimates established and negotiated for providing a medical home for children with special healthcare needs in several pediatric practices. These estimates contribute to a growing national consensus on the cost of a medical home, which is expected to result in increased reimbursement for providers wishing to implement medical homes. Preliminary practice level data are now available to demonstrate the impact of the medical home on outcomes for children with special healthcare needs and their families. Projects in 13 communities have demonstrated medical home models and developed strategies to increase "medical homeness:"at the practice level.

The Functional Outcomes Study recently reported that care that is coordinated, comprehensive, accessible, and family-centered is associated with parents' perceptions of better access to care and more respectful care.

What are the benefits of a medical home?

Child healthcare professionals and families agree that children with special healthcare needs benefit from having a medical home. The Functional Outcomes Study recently reported that care that is coordinated, comprehensive, accessible, and family-centered is associated with parents' perceptions of better access to care and more respectful care. Moreover, the medical home is associated with improved outcomes of care, with more optimal health, behavior, and cognitive development. It has been demonstrated, especially among children from low-income families, that long-term personal relationships with primary care physicians who coordinate their care provide important benefits. As Dr. Hirsch found in his research, which he reported in 1998, implementation of a medical home can lead to a decrease in rates of hospitalization, as well as lengths of stay.

How can families help?

Much work needs to be done to attain our goal of medical homes for all children with special healthcare needs, and families will play a critical role in accomplishing this goal. Families are key to promoting medical homes at the practice, policy, and political level and accomplishing our goal of a medical home for every child. Families are best able to communicate with other families about the benefits of a medical home and most effective in advocating for the needs of their children. They also have an important role to play in educating healthcare professionals around the changes in attitudes, behaviors, practices, and procedures that are needed to truly implement medical homes. In order to ensure that all families feel welcome and comfortable in medical homes, a diversity of families need to be involved in this effort. As stated by one physician participant in "Listening to the Voices of Experience: Medical Home Training and Resource Project," "The real way to make change is to have families know what they can expect good care to be and to be able to facilitate that kind of care in their physician." ■

Dr. Merle G. McPherson, MD, MPH, is currently the Director of the Division of Services for Children with Special Healthcare Needs in the Maternal and Child Health Bureau (MCHB), Health Resources and Services Administration, U.S. Department of Health and Human Sevices. During a long and distinguished career, Dr. McPherson has created a new model of healthcare delivery for children with special healthcare needs.

Gloria Weissman is the Deputy Director, Division of Services for Children With Special Health Needs in the Maternal and Child Health Bureau.

Bonnie Strickland, PhD, is the Chief of Integrated Services Branch in the MCHB's Division of Services for Children with Special Healthcare Needs (DSCSHN). This program provides national leadership to assure accesss to comprehensive healthcare (medical home) for children with special healthcare needs, appropriate financing for health and related services, community service integration, family professional partnership, cultural competence, newborn hearing screening, and adolescent transition.

MCHB

RESOURCES
More information on the medical home concept can be found on the AAP Web site at http://www.aap.org.
Select "Community Pediatricians." on their home page. You can also e-mail the AAP at docp@aap.org.

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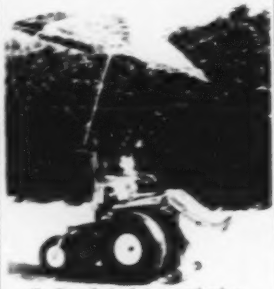

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Jeremy
Joins the Bunch

by Lacey Nicole Hittle

My brother Jeremy, 2, has a disorder called Ohdo blepharophimosis (OB). That means he will probably not be able to walk, talk, sit, or stand at the time a "normal" baby would. He uses hearing aids and has a cleft palate. Jeremy also has hypothyroidism, which means he has to get his blood tested every once in a while to make sure it does not get worse. If it does, his lips or tongue can get swollen and stay like that.

My brother may have some problems but that does not mean he is not cute, cuddly, and precious. When we get in his face, he laughs, coos, and smiles. He cuddles and holds your hand when you rock or hold him. We lie on the floor by each other and read and play with his toys. When I read to him he laughs a lot, and I like to hold him after he falls asleep.

Jeremy also likes to kiss and give me kisses. And we love to play "patti-cake" and "this little piggy" together. I am so glad we adopted him.

My parents adopted Jeremy from a family in California about two years ago. My mom and I were the ones who flew there and brought him back here to Indiana. But not only did we add Jeremy to our family, we added his birth family, too! They are now our very good friends, and we see them about three times a year, usually between New Year's and Christmas. I think they like that I am now Jeremy's older sister because they comment on how attached Jeremy is to me. I feel lucky to have so many brothers and sisters.

Even though Jeremy has OB, he can do a lot of things. He can hold his head up, roll over, and the pillow we bought him helps him sit. I am very happy because of all the things he can do. I don't really care about what he can't do. My wish for him is that he will grow up and do as much as he can and have a happy life. ■

Lacey and Jeremy live with their parents, Dawn and John, their brothers and sisters, and their pet dalmatian, Petey, in Indianapolis, IN.

Editor's Note: Children with OB often have very low muscle tone. Major feeding problems can occur, which require tube feeding. Children with OB generally have decreased movement overall, especially in facial muscles. Some children have heart problems, and some are missing a part of the brain called the corpus callosum. For more information, contact the **Ohdo Syndrome Family Network at:**

36 Borrowdale Ave., Gatley, Cheadle SK8 4QF, England; Phone: 0161-428-8583; E-mail: sevill43@hotmail.com: Web site: http://www.cafamily.org.uk/Direct/o11.html.

MOM'S TURN

Lacey Hittle's mom, Dawn Nowakoski, sheds light on the special relationship shared by Lacey and Jeremy: "Maybe it's because she went with me to bring him home and was actually the first person in our family to see him that she has a very strong bond with him. Lacey jokes that when she's grown and on her own, she's taking Jeremy with her."

"Jeremy is growing and thriving beyond our expectations," continues Dawn, "and with the love of my husband, myself, and his seven siblings, we can only expect him to continue to thrive. Lacey's essay is just one piece of reassurance that we made the best decision when we decided to adopt Jeremy."

The Children's Page welcomes contributions from children who have **disabilities**, their siblings, and their friends. Be creative! Send your stories, photos and/or artwork to: Children's Page, Exceptional Parent, 555 Kinderkamack Road, Oradell, NJ 07649-1517. Be sure to include your name, address, and daytime telephone number! Now on the Web! We will now be including **Familiar Faces** and **Children's Page** on our Web site, www.eparent.com. Please send us your photographs with the understanding that doing so gives Exceptional Parent permission to put the photos on the Exceptional Parent Web site, exactly as they appear in the magazine and with the same text.

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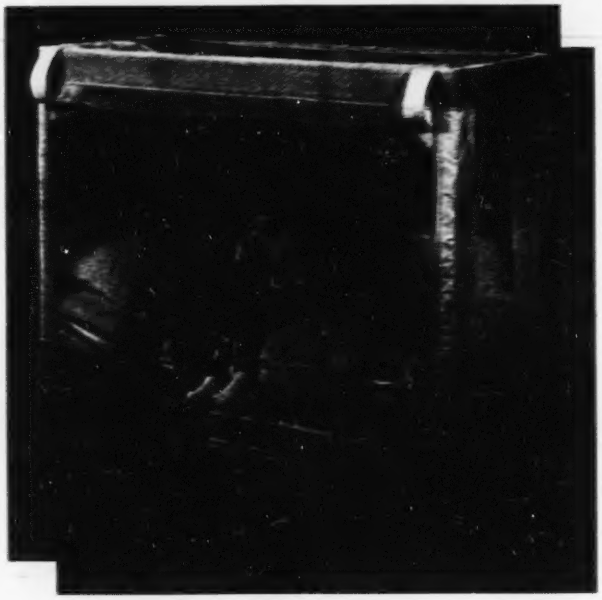

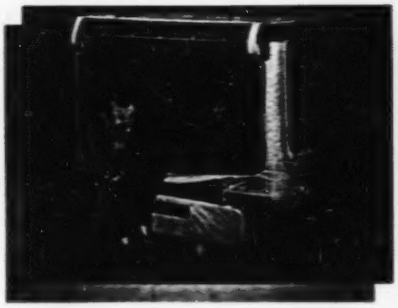

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